UNIVERSITY OF CAPE TOWN

FACULTY PUBLIC HEALTH AND FAMILY MEDICINE

MPhil Palliative Medicine

An evaluation of a psychosocial intervention for orphans on HIV Treatment: a Phase II RCT of Memory Work Therapy at PASADA, Tanzania

THESIS REPORT

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Declaration

I Elvis Joseph Miti declare that this thesis is my own work and has not been submitted for any similar award in any other higher Learning Institution.

Elvis Joseph Miti

Principal Investigator's Signature

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Dedication

This thesis is dedicated to all children, especially adolescents living with AIDS at PASADA. I have the empathy of the struggle they have to live with AIDS at a time when they have to realize who they are as individuals and members of the society. Represented by the children who took part in this project, it is their efforts to contribute in finding and documenting the adequate and sustainable treatment and care for all those who have AIDS and other limiting and threatening illnesses.

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Abbreviations

AIDS	Acquired Immune Deficiency Syndrome
ANCOVA	Analysis of covariance
ART	Antiretroviral Treatment
BSI	Brief Symptom Inventory
CD4	Cluster of Differentiation 4
CONSORT	Consolidated Standards of Reporting Trials
CPC	Children's Palliative Care
CTC	Center of Treatment and Care
FBO	Faith Based Organization
FCC	Family Centered Care
FGD	Focus Group Discussion
GSI	The Global Severity Index
HCP	Healthcare Providers
HUMULIZA	The word "HUMULIZA" is kihaya and means Console. Humuliza is as non-governmental organization registered in Tanzania
KCMC	Kilimanjaro Christian Medical Centre
KIWOHEDE	Kiota Women's health and Development
MoHSW	Ministry of Health and Social Welfare
MTCT	Mother to Child Transmission
MVC	Most Vulnerable Children
MWT	Memory Work Therapy
NACWOLA	National Community of Women living with HIV
NCPA	National Costed Plan of Action
NIMR	National Institute of Medical Research (Tanzania)
OIs	Opportunistic Infections
OVC	Orphaned and Vulnerable Children
PASADA	Pastoral Activities and Services for AIDS Dar-Es-Salaam Archdiocese
PEPFAR	President's Emergency Plan for AIDS Relief
PLWHA	Persons living with HIV and AIDS
PSS	Psychosocial Support
RCT	Random Controlled Trial
REPSSI	Regional Psychosocial Support Initiative
RSES	Rosenberg Self- Esteem Scale
SDQ	Strengths and Difficulties Questionnaire; Goodman 1997
SEQC	Self-Esteem Questionnaire for Children
TUKI	Tasisi ya Uchunguzi wa Kiswahili
UCT	University of Cape Town
UNAIDS	United Nation AIDS
WAMATA	People in the Fight Against AIDS in Tanzania
WHO	World Health Organization

Executive Summary

Rationale and aim

Pastoral Activities and Services for AIDS[1] Dar-Es-Salaam Archdiocese (PASADA) in Tanzania, is one of the beacon centers of Palliative Care in Africa. One of its health services is Memory Work Therapy (MWT) to children including orphans with AIDS. There has been, however, no previous rigorous evaluation done. There was, therefore, an opportunity for an ethical "natural experimental and wait-list groups" for a Random Controlled Trial (RCT) Phase II. The aim was to determine and document whether MWT improves *psychosocial* outcomes for orphaned children on Antiretroviral Therapy (ART), in terms of their self-esteem and coping skills as part of multidimensional[2] well-being in palliative care.

Objectives

1. To measure psychosocial well-being (i.e. needs) of orphans on HIV and AIDS treatment before attending the MWT
2. To investigate the use of copying skills learnt in MWT and understand children's experience of the interventions
3. To evaluate the groups in terms of self-reported outcomes compared to existing standard care[3] (without MWT).

Method

This was parallel design—RCT Phase II for 48 fully orphaned adolescents who are AIDS patients and on ART. It was a 24 months study, but the period of participation of the children was from January to June (6 months) 2013. The experimental and wait-list groups had 24 participants each. The trial used four questionnaires aligned to psychosocial wellbeing: the Brief Symptom Inventory (BSI), the Rosenberg Self- Esteem Scale (RSES), the Strengths and Difficulties Questionnaire (SDQ Goodman 1997) and the Self-Esteem Questionnaire for Children (SEQC). We conducted Two Focus Group Discussions (FGD). The trial used both qualitative and quantitative data collection and analysis methods. The trial analyzed quantitative data by comparing scores at each time-point using

[1] Acquired Immune Deficiency Syndrome
[2] Physical, Psychological, Social and Spiritual health situation
[3] This is the ordinary/mainstream treatment and care of HIV and AIDS according to the policy and plan of the Ministry of Health and Social Welfare (MoHSW) in Tanzania in which MWT is not stipulated. (NATIONAL POLICY GUIDELINES FOR COLLABORATIVE TB/HIV ACTIVITIES and Third Health Sector HIV and AIDS strategic Plan HSHSP III 2013-2017)

parametric and non-parametric comparison of means and ANCOVA. For the qualitative data from FGD, we subjected the data to basic thematic analysis to determine the experience of the participants and suggestions to refine MWT.

Results

The trial was successful because MWT indeed improved outcomes of the experimental group, the two groups were comparable at Time 0 (T0). There was a difference between groups on CD4 count (P=0.005) and so we adjusted for that. There was a difference only for BSI (P=0.027) total score on the baseline. At Time 1 (T1) and Time 2 (T2) follow up, the B value increased, indicating significant difference between the two groups. For example the B value for BSI at T1 was B=44.985. AT T2 however, it got bigger to B=46.668. The same occurred to RSES with B=-1.922 at T1 to B=-4.392 at T2, SDQ Goodman 1997 total difference of B=4.803 at T1 to B=5.218 at T2, SEQC: *social scale* B=-4.539 at T1 to B=-7.791 and *emotional scale* from B=-5.803 at T1 to B=-9.007 at T2. The children showed they had learnt different MWT skills including the use of memory books and boxes and they enjoyed the MWT process. The informal caregivers registered major improvements in the attitude of the children toward living with AIDS and the general social relationship with their families. The two FGD recommended MWT to other children on ART.

Discussion

With the above results, the intervention is acceptable and works very well and the participants liked it. It is very important to encourage different organizations that provide palliative care to have trials as a routine care activity in palliative care intervention. This is because it provides the much needed information for best practices in palliative especially in children.

Conclusion and recommendations

This has been the first ever audit of Psychosocial Support (PSS) in Palliative Care in PASADA and the outcome generated information on how children benefited and the feasibility of a Phase III trial. We achieved the aim and reached all the three objectives of the trial. Since this trial shows that MWT works very well for children on ART, it should give a new impetus to Repssi, PASADA and other stakeholders to step up their efforts and continue conducting MWT to AIDS patients. PASADA now has documented evidence-based data on MWT in Palliative Care beyond HIV as recommended by R. Harding et al in *"The status of paediatric palliative care in sub-Saharan Africa: An Appraisal"*

1 CHAPTER ONE

1 Introduction and Literature Review

1.1 Introduction

Like many countries in the Sub-Saharan region, the Tanzanian government has made a lot of efforts in the fight against AIDS (Omony S and Muhimbura P, 2010). This has enabled many organizations to provide different health services including Psychosocial Support (PSS). MWT as part of PSS is one of the therapies that are widely used by different organizations including PASADA(Pact Tanzania, 2011). For over 8 years, at least 48 children and adolescents have received MWT each year. While Repssi is promoting and mainstreaming PSS in healthcare (Repssi 2008), Palliative Care approach gives Repssi a better platform to promote PSS. This is because PSS is an essential medical approach in Palliative Care(Graham & Clark, 2008). The challenge is, however, Palliative Care in most African countries especially in Tanzania is a new approach (Nanney et al., 2010). This means there are some Palliative Care services that are provided to the patients but hardly any documentation is done. This is especially true in the treatment and care of AIDS. Palliative Care is equipped to deal with different co-morbidities especially among orphaned children and adolescents living with AIDS. Studies however, show that hardly any evidence based data is available in this area (Harding & Sherr, 2010). PASADA is one of those organizations providing MWT but has hardly done any audit. This RCT Phase II report provides the first ever audit of MWT at PASADA. This report format is mostly according to Consolidated Standard of Reporting Trials [CONSORT] statement—non-drug trial. It is divided into 5 Chapters. The literature review in Chapter 1, defines the area and documented views on this study and MWT integration in Palliative Care. Chapter 2 mainly provides the rationale and the statement of the problem. The method is in Chapter 3 providing information on how the study adhered to CONSORT requirements of trial report. The findings are in Chapter 4 before Chapter 5 that presents the discussion, the conclusion and the recommendations.

1.2 What is Palliative Care ?

1.2.1 World Health Organization Definition

In figure 1-1 below, the World Health Organization (WHO) provides a general definition of Palliative Care, but clearly shows why Children's Palliative Care is different though very much intertwined in the overall definition. This is to ensure that the general definition should not override

the necessity of Palliative Care for children, thereby making it clear how children should receive Palliative Care (Himelstein et al., 2004). WHO reached this definition of Palliative Care not so long ago in the late 1990s, but its application has gone a long way especially in supporting children living with AIDS. It was because of this PASADA found it very easy to take up the Palliative Care approach as one of its health services as early as 2002 (PASADA, 2009).

Figure 1-1 WHO Definition of Palliative Care (Graham & Clark, 2008)

Palliative Care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative Care :
Provides relief from pain and other distressing symptoms;

- *Affirms life and regards dying as a normal process;*
- *Intends neither to hasten or postpone death;*
- *Integrates the psychological and spiritual aspects of patient care;*
- *Offers a support system to help patients live as actively as possible until death;*
- *Offers a support system to help the family cope during the patients illness and in their own bereavement;*
- *Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;*
- *Will enhance quality of life, and may also positively influence the course of illness;*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.*

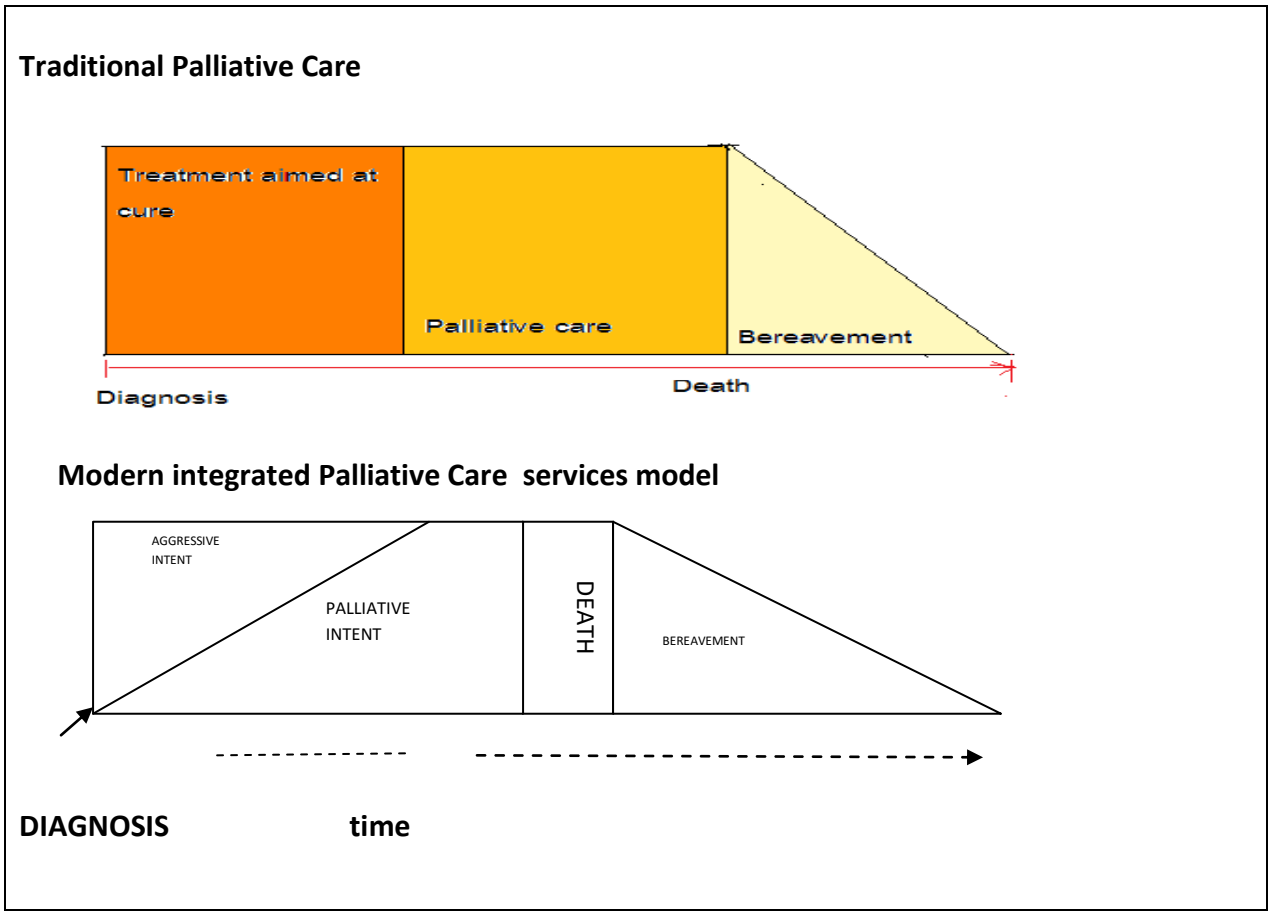
Palliative Care for children represents a special, albeit closely related field to adult Palliative Care. WHO's definition of Palliative Care appropriate for children and their families is as follows; the principles apply to other Paediatric chronic disorders

- *Palliative Care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.*
- *It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.*
- *Health providers must evaluate and alleviate a child's physical, psychological, and social distress.*
- *Effective Palliative Care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.*
- *It can be provided in tertiary care facilities, in community health centers and even in children's homes.*

1.2.2 Traditional and Modern Palliative Care

Like any other healthcare practice, Palliative Care is undergoing many different changes. There is therefore the traditional Palliative Care model that was a *"palliative switch point"* at which aggressive curative intervention ceased and palliative treatment began (Renee et al., 2009). Today, however, we approach Palliative Care from a more holistic and continuous process of treatment and care including dying and after death. This is when treatment and care begins from diagnosis where aggressive curative care is integrated with other types of care, such as psychosocial and spiritual support through to the point when curative care is not necessary (Meiring, 2010). Figure 1-2 below illustrates the different between the old and modern approach in Palliative Care:

Figure 1-2 Traditional and Modern Models of Palliative Care



With AIDS being among many other different chronic illnesses (Close & Rigamonti, 2004), it certainly has life limiting and threatening effects especially on children and adolescents. It is therefore very important to have a holistic care approach that will not only look at the aggressive curative care at one point and then Palliative Care (Hons & Sharp, 2007). If the aggressive curative care would only be the approach at the being of intervention, it would leave out important symptom control, mental health, spiritual and other non-pharmacological support. Missing out this at the onset, could lead to a spectrum of problems such as stress and poor adherence to medication. It would also be very difficult to come up with the goals of care that require the felt need contribution of the family members of the patients and other professionals from whom the patients and the family should benefit. Since modern Palliative Care requires that treatment and care begins from diagnosis through to intervention, pre and post bereavements (Himelstein et al., 2004), it is a more superior approach than the traditional one in caring and supporting especially for fully orphaned children living with AIDS.

1.3 Brief Origin and development of Palliative Care

Since the foundation of Palliative care by the late Dr Dame Cicely Sunders (1918-2005) in 1967 at St. Christopher's' Hospices in United Kingdom, many efforts have been done to ensure that people with life limiting and threatening illnesses receive holistic care to improve their quality of life(Bruera & Vignaroli, 2006). In trying to reach the goal of Palliative Care, different initiatives have been made by different organizations on international national levels. On international level, the Association of Children's Palliative Care of UK is one of the first organizations to work out a network for children's palliative care. This was the International Children's Palliative Network (ICPCN) charter of rights for life limited and threatened children that started around 2005 (Renee et al., 2009). It is however very important to emphasize the that fact World Health Organization (WHO) definition of palliative care pushed this important health service for international recognition already in the late 1990 (Graham & Clark, 2008). It was for this reason it was relatively easy to find different way to promote palliative care in Africa and Tanzania (National level) in particular despite the different challenges that we are facing.

1.4 Development of Palliative Care in Africa and at PASADA

There are many efforts that are being done to improve health services in Africa. This is evident is the different initiatives that have been invested to promote Palliative Care in Sub-Saharan Africa. These efforts could be traced from the Cape Town Declaration of 2002 in which Palliative care was declared a human right for both adults and children (African PalliativeCare Association, 2011) in South Africa.

According to Nanney, however, even though there is no clear official policy on Palliative Care in Tanzania, we could trace Palliative Care from the early 1990s. Different efforts have since been done to ensure patients and their families have access to this important healthcare service. Through the support of PEPFAR, the Evangelical Lutheran Church of Tanzania (ELCT) has provided Palliative Care through Care for PLWHA in Tanzania (CHAT) since 2007. This program was coordinated by the Selian Lutheran Hospital in Arusha. There is also Palliative Care in Tanga at Muheza hospital and efforts are underway to improve the existing health services related to Palliative Care at Kilimanjaro Christian Medical Center (KCMC) in Moshi (Nanney et al., 2010)

Until recently, it is not clear whether the Ocean Road Cancer Institute is providing Palliative Care or not, despite the large number of advanced cancer patients receiving treatment and care from there. The institute has however, been working with the government and different organizations including WHO, to work on different ways of providing Palliative Care to patients and come up with a national policy on Palliative Care (Diwani, 2012). In the efforts to coordinate and promote Palliative Care in Tanzania, Tanzania Palliative Care Association (TPCA) was founded in 2004 and registered in 2006 (Tanzania Palliative Care Association, 2012)..

Despite the absence of a clear policy on Palliative Care and restrictions on the distribution of Oral Morphine, there are however, many efforts to evaluate the efficacy of providing Palliative Care in Tanzania. It is therefore important to acknowledge the different institutions in Tanzania that continue providing Palliative Care despite many challenges. It is also very important to acknowledge other different organizations such as the Foundation for Hospices in Sub-Saharan Africa (FHSSA) and the African Palliative Care Association (APCA) for their efforts to promote Palliative Care in Tanzania (Hartwig et al., 2014).

It from this background we can consolidate the development of Palliative Care in Africa and the Sub-Sarahan in particular. The best way to do that was by establishing some institutions in this region that could spearhead these efforts. This meant there was the need to make effective selection of institutions that have a good background in providing health care to people especially children with life limiting and threatening illnesses. There would soon be three organisations called Beacon Centers of palliative care in Africa. These centeres were established in Tanzania, Uganda and South Africa in 2009. In Tanzania the responsibility was intrusted to PASADA, in Uganda to Mildway and in South Africa to the Hospices Palliative Care of South Africa. With funding from Princess Diana of Wales foundation, those three organisations have been training different health care workers to introduce Palliative Care especially Children's Palliative Care (CPC) in their health institutions. By the year 2013 about 227 health care workers had enrolled in CPC training in the different centers and 199 (52%) completed the training through workshops, mentorship and placements and written examination(Downing et al., 2013)

Even though PASADA was nominated as one of the Beacon Centers of Palliative Care in Africa only in 2009, its efforts began as early as 2002. Using the Family Centered Care model (FCC), PASADA

has been providing Palliative Care for HIV and AIDS patients. With more than 24 satellite Centers for Treatment and Care (CTC), the organization has reached most of the PLWHA in Dar-Es-Salaam and its peripheral areas. Most of the funding came from Princess Diana of Wales (PASADA, 2009). PASADA through its Palliative Care Unit has since been providing Children's Palliative Care (CPC) training to different (Health Care Providers) HCP in Tanzania (ICPCN, 2011).

"PASADA runs a project supporting children affected by HIV/AIDS, including those who are HIV Positive'(Pact Tanzania, 2011). This is in line with the HIV and AIDS (Prevention and Control) Act (NO. 28 of 2008) of Tanzania (Omony and Muhimbura 2010). With the introduction of the (National Costed Plan of Action for children in difficult circumstances) NCPA in 2007 that stipulated PSS as one of the thematic areas of intervention (Republic, 2010), it gave PASADA a new impetus to ensure that its patients receive PSS not as an optional healthcare service but as part of Holistic care approach. This fits well with the development of Palliative Care at PASADA. It is for the above reasons, PASADA has through the Orphaned and Vulnerable Children's (OVC) Department continued running sessions of MWT for more than 8 years for the Most Vulnerable Children (MVC) including those who are partially or Fully Orphaned children.

1.5 Palliative Care for children and young people with HIV and AIDS

1.5.1 Why the focus on adolescents with AIDS?

As much as adolescents are a unique population, living with AIDS during such an important process of growth, entails facing many challenges. It is for this reason we should link them to different available health services and resources to help them effectively sail through their adolescence. Close and Rigamonti rightly put it when they indicate that the ever-increasing accessibility to Antiretroviral treatment becomes more widely available, it means that HIV-infected children are now provided with the opportunity to mature into young adults. They have to make critical decisions and turning points for which proper guidance is often needed (Close & Rigamonti, 2004). WHO clearly confirms this in the 2013 report on adolescents and AIDS as shown in figure 1-3:

Figure 1-3 Adolescents and AIDS by 2013

25 November 2013 -- More than 2 million adolescents between the ages of 10 and 19 years are living with HIV, and many do not receive the care and support that they need to stay in good health and prevent transmission. In addition, millions more adolescents are at risk of infection. The failure to support effective and acceptable HIV services for adolescents has resulted in a 50% increase in reported AIDS-related deaths in this group compared with the 30% decline seen in the general population from 2005 to 2012. New WHO recommendations released in the run-up to World AIDS Day 2013 are the first to address the specific needs of adolescents, both for those living with HIV and those who are at risk of infection.(WHO, 2013a)

The other important aspects is the way adolescents look at death, especially during this time when a good number of them have been orphaned deal to parents' high mortality rate related to AIDS (King et al., 2009). Figure 1-4 below, provides some details of how adolescents view death:

Figure 1-4 How adolescents view death

Adolescents have an adult understanding of death, but an actual death shatters their view of immortality. They believe they are invincible and that nothing "bad" will happen to them or their friends. They often engage in risk-taking behavior, seeming to test the limits of that immortality. When a friend does die, they are outraged. Unlike preadolescents, adolescents can be highly emotional and may respond by sobbing, angry outbursts and destructive behavior. They do not want to be different from their peers and may be embarrassed by a death of a parent or sibling. They need to grieve with their friends and ritualize in their own way. Although they may not be sharing their grief with adults, it is extremely important that the adults in an adolescent's life are there for them in care and support(Deborah Rivlin, 2012).

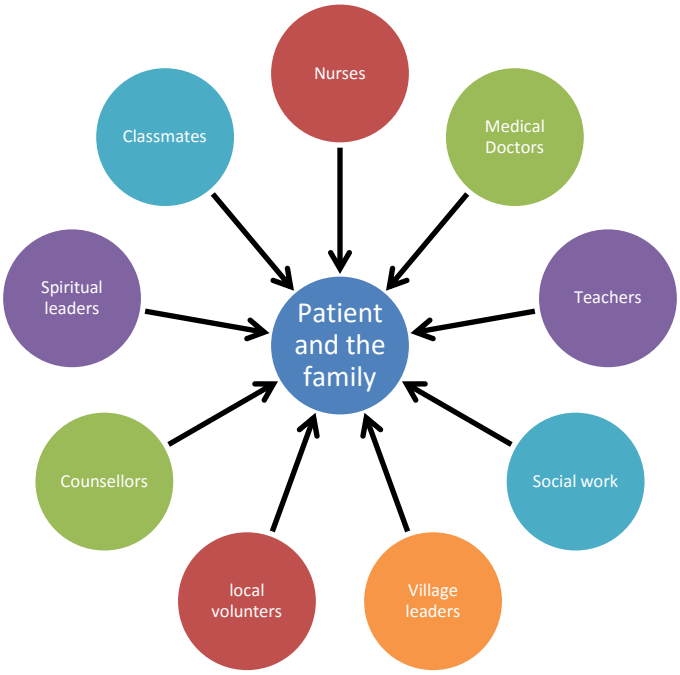
With these complex challenges that children and adolescents who are directly or indirectly affected by AIDS, they and their caregivers will increasingly need many different kinds of support so that they could be empowered with knowledge and skills to cope with such situations (Snider & Dawes, 2006). This is to help children and adolescents living with AIDS and their families who need to *"deal with its infectivity, its long latent period, its tendency to decimate the whole families and the fact that it is still highly stigmatizing"* (Renee et al., 2009). This exposes the children and adolescents with different developmental, economic and psychosocial problems (King et al., 2009). Tanzania through The HIV/AIDS Prevention and Control Act No. 28 of 2008 has clear laws, policies for prevention, care and treatment, and protect the rights of PLWHA including children and adolescents (Tanzania Palliative Care Association, 2012). Those are some of the reasons Palliative Care for children and adolescents with AIDS, is well placed to meet some of their most important needs and Michelle Meiring makes a clear observation as to why palliative care is very important to children and youths as shown in figure 1-5:

Figure 1-5 Why Palliative Care for adolescents?

Palliative Care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, Embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement(Meiring, 2010).

With the above approach to treatment, care and support, we assure children and adolescents long lasting quality of life despite the challenges of living with HIV and AIDS. It is at this juncture MWT becomes very instrumental in the process of ensuring they have stable physical, emotional, social and spiritual stamina in dealing with challenges related to living with HIV and AIDS (USAID Aidstar-one, 2011). This is in line with Repssi whose approach in PSS is addressing the effects of the pandemic by paying attention to both its psychosocial and biomedical aspects (Repssi 2008). If children and adolescents living with AIDS receive proper Palliative Care, they could live a normal life like any other person where the illness is well managed by different stakeholders (Renee et al., 2009). The management of the patients and their families should be through an interdisciplinary approach. This entails ensuring the patients and their families are given the widest possible and available means to come up with different goals of care to improve their quality of life (Bruera and Vignaroli 2006). This means depending on a given environment, the patients and their families will benefit from a well-coordinated team of Social Workers, Medical doctors, Nurses, Counselors, Teachers, local leaders, Village volunteers, Spiritual leaders and so forth. A typical interdisciplinary team in Tanzania could be graphically presented as shown in figure 1-6:

Figure 1-6 Typical interdisciplinary team in Tanzania



With the patient and the family the focus of all the available professionals in a given health center or community, a forum in which the holistic well-being of the patients becomes possible (Ahmedzai et al., 2004). This is especially very important to fully orphaned children and adolescents whose families would need Palliative Care to stabilize their family devastated by AIDS (Renee et al., 2009).

1.5.2 Palliative Care, HIV and AIDS

1.5.2.1 What are HIV and AIDS?

Human Immunodeficiency Virus (HIV) is a virus that causes Acquired Immunodeficiency Syndrome (AIDS). The virus attacks the human immune systems making it very difficult for the body to fight different infections and diseases. Depending on the stage of the infection, especially in stage 4, the white blood cells that compose the defense system of the body become so weak and less such that they cannot fight any infections called Opportunistic Infections (IOs) and other diseases (World Health Organization, 2007)

This virus is transmitted through unsafe or unprotected vaginal or anal penetrative and oral sex. The virus could also be transmitted through transfusion of contaminated blood from an infected person to non-infected person. It can also be transmitted by sharing contaminated needles, syringes and many other sharp items among or between infected and non-infected persons. There is however, the most dangerous mode of transmission, which is from an infected mother to her baby at three levels. An infected mother, could transmit the virus to an unborn baby during pregnancy; she can transmit the virus to the baby during birth and during breast-feeding.(World Health Organization, 2007)

When the virus is not controlled or treated, it causes AIDS within a period of 5-10 years and this depends very much on the stamina of an individual patient. This is the manifestation of the disease in four major stages (WHO, 2007):

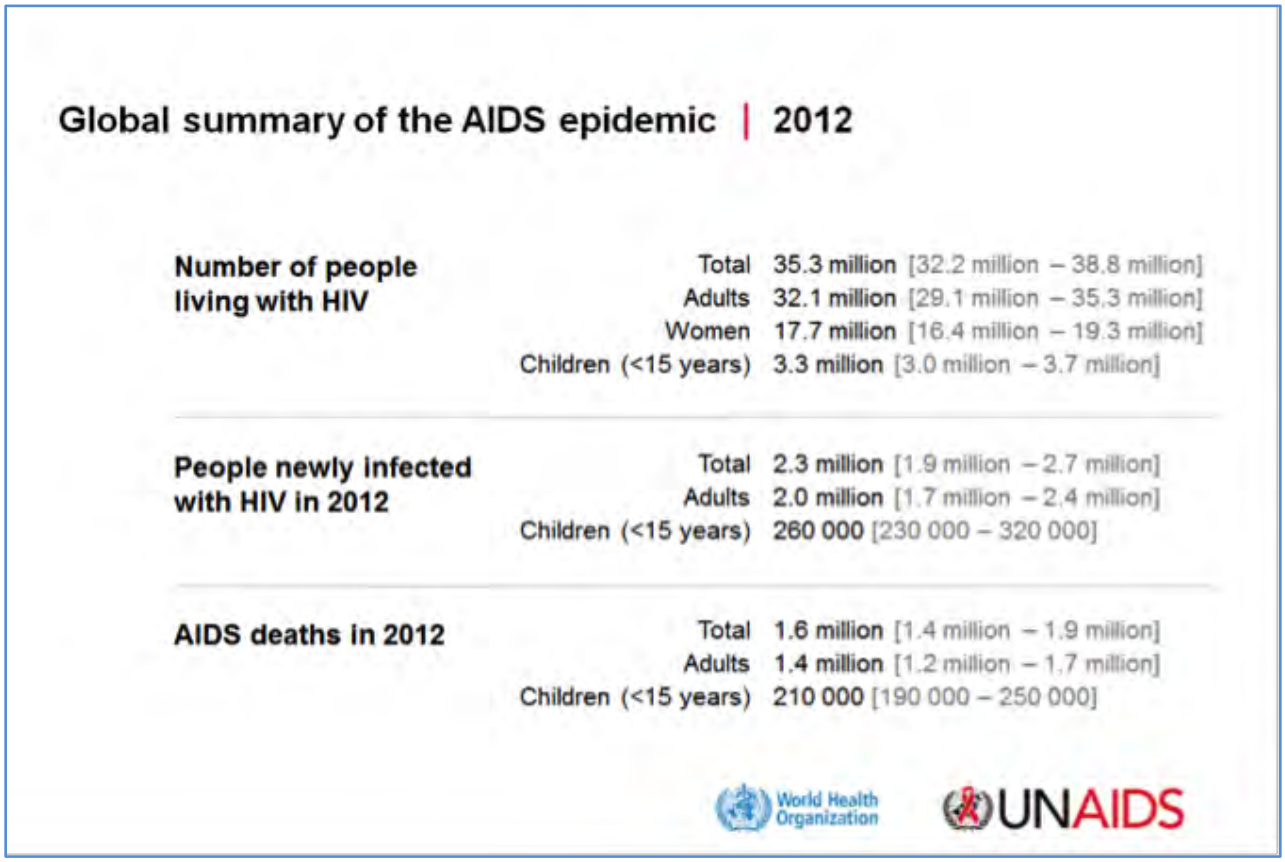
- Stage 1 is the asymptotic and acute retroviral syndrome or Persistent generalized lymphadenopathy (PGL);
- Stage 2 (mild symptoms) is associated with infections related to the skin, Fungal nail infections of fingers, diarrhea, and loss of weight by more than 10%;
- Stage 3 (advanced symptoms) is associated with lung infections such as Lung TB and gastronomical infections;
- Stage 4 (Severe symptoms) is terminal is which the patient experience very serious life threatening infections such Extra-pulmonary TB

HIV and AIDS have not paired children and youth and since this disease is currently not curable, the children and youth certainly need palliative care approach through which they could be treatment and care of this disease. There are over 3.3 million (WHO, 2013b) children who are living with AIDS and deal to its long latency period, the children and their families face many challenges related to their physical, psychological, sociological and spiritual wellbeing. It is because of this reason palliative care is very instrumental to help those patients and their families build resilience to live a quality life in all the different stages of HIV and AIDS (Scrimgeour, Marston & Boucher, 2010)

1.5.2.2 Global trend of AIDS

About 35 million people worldwide live with AIDS (WHO, 2013b) . Figure 1-7 below provides some details:

Figure 1-7 Global Summary of the AIDS epidemic 2012



According to the UNAIDS Regional Fact Sheet of 2012, *"more than 90% who acquired HIV in 2011lived in Sub-Saharan Africa"*(UNAIDS, 2013c). Unfortunately, Tanzania is in this region and there are different efforts that are being done to ensure that patients, especially children and ado-

lescents build resilience against AIDS, even though there is hardly any documentation beyond HIV in Palliative Care.

1.5.2.3 Tanzania trend of AIDS

According to Pact Tanzania in 'Sharing the Lessons, Tanzania's National Orphans & Vulnerable Children (OVC) Program under PEPFAR I [first Phase from 2004-2009], "*Tanzania, like other Sub-Saharan countries, continues to be deeply affected by HIV and AIDS"* (Pact Tanzania, 2011). Even though there is evidence that the new infection rate among children has reduced by 50% in Eastern and Southern Africa, Tanzania is among Uganda and Lesotho where the rate has stagnated or increasing (UNAIDS, 2013a). Tanzania has a population of approximately 45 million people (World Population Review, 2014). The current HIV/AIDS prevalence rate is 5.3% but may be much higher among women. There are also different variations from region to another. For example Manyara in Arusha Region is rated at 1.5%, but as high as 14.8% in Njombe (Tanzania, 2014). Estimates show there are 1,400,000 people living with HIV and AIDS and among these 250,000 are children between 0 and 14 years of age. Deriving from UNAIDS (UNAIDS, 2013b), table 1-1 shows the status of HIV and AIDS epidemic in Tanzania by 2013:

Table 1-1 HIV and AIDS status in Tanzania 2013

Item	Range	Average	Percentage
Number of people living with HIV	[1,300,000 - 1,500,000]	1,400,000	100
Adults aged 15 to 49 prevalence rate	[4.6% - 5.3%]	5.00%	
Adults aged 15 and up living with HIV	[1,100,000 - 1,300,000]	1,200,000	85.71
Women aged 15 and up living with HIV	[640,000 - 750,000]	690,000	49.29
Children aged 0 to 14 living with HIV	[210,000 - 280,000]	250,000	20.83
Deaths due to AIDS	[69,000 - 90,000]	78,000	5.57
Orphans due to AIDS aged 0 to 17	[1,200,000 - 1,500,000]	1,300,000	92.86

Putting the UNAIDS figures in percentages, it is evident that the children are the most affected with about 93% orphaned deals to AIDS. About 21% living with AIDS but it is important to note that table 1-1 does not look at adolescents up to 18 years of age. If this would be included, the number would increase. It is therefore imperative to provide children and adolescents with Palliative Care to help them cope with this situation and if there are any efforts done in Tanzania especially in the provision of PSS, we need to ensure documentation.

1.5.3 Memory Work as a coping strategy for children with HIV and AIDS

1.5.3.1 Brief history of Memory Work

Memory Work has developed so much to include different tools that children and adults are using today to cope with the different psychosocial problems. It all started with the memory book in the United Kingdom by children's charity Barnardo's as early as 1988. It was a response to support African parents in the United Kingdom affected by HIV and AIDS to make plans for the future of their children. With the challenges of HIV and AIDS at a time when suffering from this illness would mean dying soon, many parents, especially from Sub-Saharan wanted to ensure their children had a clear description of what would happen to them especially that they were staying away from their relatives in Africa. The parents did this through the '*Positive Position'* program. This program helped the parents who had AIDS to write a *'Will'* and ensure their children would have somewhere to stay when they died. By 1998, Memory Work had reached Uganda with more emphasis put on improving ties between the children and their parents living with AIDS. It was mainly to help the children and their parents fight discrimination and stigma. This was strengthened through the NACWOLA Memory project (Medicus Mundi Schwiez, 2005).

Many countries today use Memory Work in Africa including Tanzania. Repssi has spearheaded the promotion of Memory Work for many years. This has been through capacity building for different organizations to provide Memory Work to different people including children and adolescents. The organization has worked on different facilitators' manuals of Memory Work and mainstreaming psychosocial support in healthcare (Repssi, 2014).

1.5.3.2 Meaning of Memory Work

There is a milliard of definitions of Memory Work from different organizations and individuals. Figure 1-8 is the Repssi definition:

Figure 1-8 Memory Work definition

> *Memory Work can be defined as creating a "safe space" in which to explore your life story as a form of "self-help" or group support. The "safe space" can be a physical space – like a room or the shade under a tree, where people explore and share their life stories just by talking. However, these spaces can also be the space on the pages of a book or on the sides of a box on which you express things about your life by writing or drawing. Memory Work draws on Narrative Therapy, which is a way of helping people to find and live out empowering parts of the stories that make up their lives. Often, when we think about our life, we think about what a battle it is. It is also easy to feel like we are losing that battle. In Narrative Therapy and Memory Work, we try to help people to recognize ways in which they are not only losing and not only victims, but also survivors and winners and heroes in their own special way. Looking for these kinds of stories is called "finding empowering plots".* (Repssi, 1999)

Jonathan Morgan provides a personal but concise definition of Memory Work when he says *"Memory Work might be described as any endeavour involving elements of remembering, retelling, recording or sharing"*(Morgan, 2004).

1.5.3.3 MWT— a copying strategy for children and adolescents with AIDS

Creating an environment is which children and adolescents are able to communicate effectively is the essence of MWT (Repssi, 1999). This is especially very important for orphaned children who are living with AIDS themselves. MWT helps the children and adolescents build stamina in the face of AIDS. "*It empowers children to cope with the impact of HIV and AIDS on the family as a whole and on their own capacity to continue positively with their lives"*(PASADA, 2008). It is for this reason MWT has been used in many organisations in Tanzania. This includes, KIWOHEDE and HUMULIZA (Pact Tanzania, 2011) even though hardly any clear documentation of this PSS provision is available beyond HIV.

1.5.3.4 Memory Work and Paediatric Palliative Care

Memory Work or '*legacy building*' whatever you may name it, is very much embodies in Palliative Care. This is a natural state by virtual of its definition, explanation and the practice. In an article written by Rebbecca A. Simontisch (Child Specialist) in ChiPPS Pediatric Palliative Care Newsletter (*www.nhpco.org/pediatrics)* in 2010, she clarifies the important of Memory Work in modern Palliative Care as quoted in figure 1-9:

Figure 1-9 Memory Work and Palliative Care

> ***The ABCs of Legacy Building***
> *Legacy building serves as an invaluable tool through which patients and caregivers alike express messages about their feelings and create tangible memories of meaningful life experiences and relationships. Utilizing legacy-building techniques, children, teens, and caregivers have opportunities for self-expression, processing feelings, and communicating their wishes, needs, and love for each other. During the intimate times, patients and family members share during legacy building, they often feel empowered, comforted, and supported.*
> *Healthcare professionals have opportunities to support legacy building with families from the onset of diagnosis until the time of death as patients receive Palliative Care services. Child Life Specialists often have a variety of different projects and materials available for patients and families that will meet special interests. Examples of legacy building include scrapbooking, journals, videos, songs, poetry, memory boxes, and hand/foot prints.* (Corr, Tarkildson & Horgan, 2010)

It is, therefore, interesting to conclude that Memory Work in Palliative Care, provides the practitioners (interdisciplinary team), the patient and the family to best customize their experiences right through diagnosis to post bereavement to maximize the quality of life of both patients and their families. This makes Memory Work in Palliative Care so powerful a non-

pharmacological intervention. It is therefore very important that Memory Work as PSS in AIDS should be documented so that we could find the best way to continue and improve it for the best interest of our patients and their families.

2 CHAPTER 2

2.1 Rationale/need for the trial

Pastoral Activities and Services for AIDS Dar-Es-Salaam Archdiocese (PASADA) in Tanzania, is one of the beacon centers of Palliative Care in Africa. One of its health services is Memory Work Therapy (MWT) to children including orphans with AIDS. There has been, however, no previous rigorous evaluation done. There was, therefore, an opportunity for an ethical "natural experimental and wait-list groups" for a Random Controlled Trial (RCT) Phase II. This study, therefore was in line with 'Other Important Recommendations' in Dr. Harding et al Executive Summary of *"The Status of Paediatric Palliative Care in Sub-Saharan Africa-An Appraisal"*. Other important recommendations No. 15 states High-quality evidence is urgently required to determine the added benefit of Palliative Care for those children accessing ART (Harding & Sherr, 2010). It is furthermore clear that is recommendation reflects the lack of data on HIV intervention of children. Most of the data deals with adult patients but, the novel fact of this trial is that it is about HIV children in palliative care.

2.2 Statement of the Problem

There are surely many efforts being done to empower children and adolescents build resilience in the face of orphanhood and living with AIDS. This is evidence of how different organizations especially in Africa would like Palliative Care to be available and accessible. It is however very important this quest be coupled with evidence-based documentation in Palliative Care practice. Harding and Sherr rightly put in figure 2-1:

Figure 2-1 Absence of repots focused on care beyond HIV

> *There is a large and robust body of evidence generated in a number of countries that demonstrates the high psychological burden and morbidity associated with bereavement and orphanhood among children in Africa … Palliative Care services are well placed, and skilled, to provide emotional support pre- and post-death of the child's significant adult….Although the issues of orphanhood and bereavement cut across diseases, almost no papers or reports focused on care beyond HIV*(Harding & Sherr, 2010)

Fortunately or unfortunately PASADA is one among such organisations that have not done any documentation beyond HIV. PASADA has been providing PSS to MVC who are partially or fully orphaned on ART for more than 8 years but no Phase II trial has been done. Unless the Phase II is done, PASADA will not have any evidence based data on how this MWT is helping its patients especially children and adolescents cope with HIV and AIDS. This means there will not be evidence

for an optimal Phase III design to scale up MWT at PASADA and other health centers that provide Palliative Care .

2.3 Aim

To determine and document whether Memory Work Therapy (MWT) improves outcomes for children who are orphaned and on Antiretroviral Therapy (ART), in terms of their self-esteem, coping and multidimensional wellbeing.

2.4 Objectives

2.4.1 To measure psychosocial well being (i.e. needs) of orphans on HIV and AIDS treatment before attending the MWT

2.4.2 To investigate the use of copying skills learnt in MWT seminars at PASADA

2.4.3 To evaluate the groups in terms of outcome compared to existing standard care (without MWT)

2.5 Research Questions

2.5.1 What is the state of psychosocial wellbeing of orphans on HIV and AIDS treatment before undergoing MWT?

2.5.2 Do orphaned adolescents use copying skills learnt in MWT seminars?

2.5.3 Was there any difference in the outcome compared to the existing standard care (without MWT?

2.6 Anticipated outcome of the study

We anticipated the children would benefit from MWT hence improve their quality of life. The outcome also would provide recommendations of size effect of optimal Phase III design.

2.7 How will the results of the trial be used?

- This study apart from helping the organization improve MWT, It will provide information on how to scale up MWT in Palliative Care.
- It will generate information on the feasibility of moving to a Phase III trial.
- The findings of this study will boast PASADA package in Palliative Care Training especially in CPC. This would encourage more people to take up Palliative Care as the main approach in Pediatrics.
- Repssi as one of the major organizations promoting the mainstreaming of PSS (Repssi, 2007)for children will find the recommendations of this study very important in their ef-

forts to improve the wellbeing of children living in difficult circumstances especially those with life threatening or limiting illnesses.

- The results will help MoHSW and the TPCA to mainstream PSS by developing policies that would make effective MWT a requirement for any Pediatric Palliative Care intervention especially for orphaned children and adolescent and their families.
- PSS is one of the key thematic areas in the NCPA. These findings will therefore contribute to those efforts since PASADA is one of the major implementers of NCPA.

2.8 Potential challenges

- Stigma and discrimination is a key challenge for successful Memory Work and is one of the important issues that the Memory Work program addresses.
- Attrition of participants because of different challenges such as failures to attend or unable to go through interview and FGD because of OIs at a given stage or death of the patient
- ART regimens could be very stress especially for adolescents and this could lead to poor participation during the therapy.
- Some children and informal caregivers may not wish the child to participate in the trial
  Budget constraints

2.9 Dissemination

We will conduct dissemination meeting at PASADA through interdepartmental debriefing meeting and CPC Training for HCP. We will present the findings at Palliative Care, PSS, AIDS and other conferences and peer reviews. The report will be available at www.pasada.or.tz

3 CHAPTER THREE

3.1 Method

3.1.1 Research Design

This was a parallel design—an RCT phase II study in accordance with Consolidated Standards of Reporting Trials (CONSORT) (Davidoff, Lang & Gastel, 2008). It compared two groups of children between the ages of 14-18 who were fully orphaned and on AIDS treatment. [In most African context, children include people who are 18 years old (Deacon & Stephney, 2004)]. These two groups were the *standard care* plus additional Psychosocial Support [PSS] through MWT (experimental condition) and "the wait-list" (control group) with *standard care* but only received MWT after an interval of 6 months. Twelve randomly selected participants (6 males and 6 females) from the wait-list group participated in FDG a week after their MWT intervention. Refer to Figure 3-1 for the trial flow.

Standard care at PASADA includes the basic or mainstream health services that every AIDS patient receives as guided by the Ministry of Health and Social Welfare (MoHSW) in HIV and AIDS care and treatments. This includes HIV and AIDS counseling, Center for Treatment Care (CTC) services such as ART, Opportunistic Infections (OIs) treatment and care and prevention of the spread of the HIV.

3.1.2 Setting

The trial took place at PASADA in the OVC and the Medical departments in Dar-Es-Salaam, Temeke, Tanzania. This was because as one of the thematic areas in the NCPA (Republic, 2010), PSS is provided to children who are affected and/or infected by HIV and AIDS. PASADA is one of the Beacon Centers for Palliative Care in Africa (ICPCN, 2011) and it is also a partner of Repssi (Repssi, 2008) which is mainstreaming Psychosocial Support for the well-being of all children including those infected by HIV and AIDS.

3.1.3 The Memory Work Therapy intervention at PASADA

For the past 8 years over 400 MVC, not necessary partially or fully orphaned children have gone through MWT. MWT could either be on daily or residential basis in a 'Safe Space' as recommended by Repssi Tanzania and PASADA. There are many such 'Safe Spaces' (places) in Dar-Es-Salaam such as Religious Convents and Retreat Centers that have provided the best environment for such activities. They provide healthy food and bedding, open places for skills demonstration, recreation

and counseling. The restriction of entry and leaving those places makes them ideal for such therapeutic seminars.

Trained Repssi Memory Work facilitators who are working at PASADA conducted/ facilitated MWT. This constituted of different HCP who are Children's Palliative Care (CPC) providers. PASADA requires all HCP working with children sign a Child Protection's oath in order to reduce possible child abuse. MWT normally has 24 participants with at least two facilitators. This is a ratio of 12 participants to 1 facilitator (12:1). This is done to adhere to the requirement of Support Group and facilitation skills (Some, 2002). We manualized the intervention to ensure we delivered MWT in a common way whilst noting the individual needs based on Palliative Care clinical intervention. This ensured attention was given to physical symptom management, psychosocial and spiritual support to both the children and their caregivers to optimize their quality of life (Ahmedzai et al., 2004). This included detailed patients- centered assessment that focuses on multi-dimensional problems, the cause, intensity, characteristics and importance to the patient. Attention was on how the children and adolescents are able to use MWT skills to build resilience against challenges related to living with AIDS (Shen, 2006).

Going through all the manuals of Memory Work produced by Repssi requires a lot of time. It is for this reason PASADA only covered the most important sessions so that the therapy does not take more than 5 days. This includes the most feasible for children, such as the Memory box, Memory book, Tree of life and the Hero (Active Citizen) book. The materials that were used included used card boxes, colour pencils, water-colours and brushes, A4 white papers, A4 assorted colour manila papers, hammers, nails, cotton wool threads, glue, seal tape and flip charts. All those materials are locally obtainable from stationeries and hardware shops. Table 3-1 shows the timetable used for MWT in the trial:

Table 3-1 Session timetable of MWT

Day	Activity	Objectives	Responsible
1	Memory Book	To prepare a space to explore life stories.	Facilitators
2	Memory box	To create another kind of space in and on which to explore your new and fresh story (a story that is not only about pain and suffering but that also notes courage, survival skills, values and hope)	
3	Tree of life	The aim of the first two parts of the Tree Of Life process is to build and acknowledge "a second story" about each child's life. The second story consists of the skills, abilities, hopes and dreams of each child and the histories of these.	

4	Hero Book	To help the children find solutions to the personal and social challenges they face.	
5	Issuing of Certificates of Participation		Coordinator

3.1.4 Inclusion and exclusion criteria

A clear Inclusion and exclusion criteria is very important in research in that it help the researcher clearly know the right kind of cohorts. It defines the boundaries of participation in the study in order not confound the interpretation and analysis of findings (Krist-Etherton et al., 1999). In this study, we could recruit a maximum of two children from a given family in order to give a chance to more families to participate. We asked prospect participants to provide some history of any residential seminar problems so that precautions such as getting some special bedding for those who bed-wet, special pharmacological support or any food allergies. Table 3-2 shows the details of the inclusion and exclusion criteria.

Table 3-2 Inclusion and Exclusion of participants

No	**Inclusion**	**Exclusion**
1	Children knowledgeable about their HIV and AIDS positive status at the beginning of the study	Children who did not know their HIV and AIDS were not admitted because participants would be required to share their AIDS experience to their fellows
2	Only Children between ages 14 and 18 were admitted at the state of the study	We did not admit any one below 14 or above 18 in the study. Children in adolescence were the study target
3	Children who never took part in any previous MWT at PASADA or elsewhere	It is a policy of PASADA for all eligible children to have MWT at least once during their adolescence. Having others to repeat would not give chance for others to have MWT and it could confound the findings
4	Fully Orphaned children—that is children whose both parents have died	Children who had either their mother or father living could not participate to ensure homogeneity of participation in terms of experience of loss of biological parents
5	Children who are on HIV and AIDS treatment (ART) at PASADA	Children who were not yet on ART at PASADA could not participate since they normally have less/different challenges in terms of adherence to medication, stage of AIDS and its physical and psychosocial challenges, stigma and discrimination. There was need for homogeneity of the participants
6	Children knowledgeable and (evidence record files at PASADA) about the death of their parents (one or both died at least 40 days ago)	We did not allow patients who did not have information on bereavement in their files. It is common in Tanzania to have the first death memorial after 40 days when more information about the death of a person is given
7	Children who are PASADA registered patients at the beginning of the study	Non-PASADA patients were not allowed since we did not have any records
8	Children were competent patients at the beginning of the study	Bedridden patients were not admitted since MWT required active participation
9	Only literate children were admitted	We did not admit Illiterate patients since they would not sign the consent form and MWT done at PASADA requires a lot of reading and writing.
10	Children who were capable of giving informed and formal written assent to participate in the study	Children who could not give an informed and formal written assent were not admitted deal to different factors including mental and physical challenges, religious and literacy
11	Children who had legal caregivers who could make an informed and formal written consent for their children to participate	We did not admit caregivers who could not make their own and children's informed consent into the study. This is because; Palliative Care requires the participation of the caregivers and the patients in the care and treatment process. The caregivers would participate in FGD
12	Only mentally normal children could participate	Since this was not MWT for Special Need Children, diagnosed psychiatric disorder children were not admitted into the study

3.1.5 Sample size and Randomization

3.1.5.1 48 participants for the Experimental and wait list groups

A sample is a number of participants taking part in a study to represent the larger study population. Three main kinds of sampling include convenient, judgment and randomization. There are different reasons why we need to use a sample in research but the most important is to make the research cost effective and manageable within a given period of time. Sampling makes it easier to meet the smaller number of participants in a shorter time with minimum financial and human resources compared to a Census that requires to study the whole population(Mugo, 2002). In this study, the study population was all the fully orphaned children and youths who are PASADA ART patients. Since this was a RCT phase II to explore feasibility and since we did not have prior data, we did not perform any formal sample size calculation. We just followed the usual two groups of 24 children each groups who participate in MWT at PASADA. In this study, there were therefore 24 adolescents for experimental and 24 for the 'wait list' or conditional groups. The trial allowed us to plot scores and appraise the intervention in terms of further refinement, as well as to explore follow-up and recruitment methods.

Randomization requires that the participants are not known by the researcher in order to give equal chance to prospect individuals to participate in a study without any biases. In clinical trials, this is very important in that it helps the researcher to get the right participants while giving equal chance to the whole study population (University of the West of England, 2011) . In this study randomization took place during different activities such as school supplies collection, students' gathering, clients' meeting (first Thursday of the Month) first Tuesday of the month pediatric clinic, and other occasions throughout the year. Children could only receive those services if they produce an OVC or CTC identity card. There were 24 pieces of papers written '1' and 24 written '2'. These papers were placed into two lunch-boxes—one for Girls and the other for Boys. Each lunch-box had 12 papers written; '1' and 12 other papers written '2'. The girls and boys who discovered they picked '1' were the Experimental group and those who picked '2' were the 'Wait list' group. This totaled to 48 participants with 12 boys and 12 girls in each group. Neither the children nor researcher decided, therefore, whether the child would attend now or later since the number picked by the child determined which group he or she would belong.

When the children and their informal caregivers agreed, they with the support from the research assistants went through an assent form (Appendix E) before the child and the informal caregiver signed it. Both the child and the informal caregiver then signed a consent form each (Appendix C and D) to be admitted into the study. If a particular child or informal caregiver could not assent and consent, randomization continued until we reached the required total sample. The children who did not wish to take part in the study continued accessing all the services provided by PASADA. In this study, only one female prospect participant did not sign and return the consent form because the grandfather could not consent. We therefore continued with recruitment and managed to meet the required number of participants.

3.1.5.2 Focus Group Discussion

We used random sampling to pick the 12 participants for the FGD from the wait list group of 24 children during their June 2013 MWT intervention. To ensure this, 12 of the 24 notebooks had the first page stained with a marker pen before distribution. Culturally, when boys and girls meet for the first time, the two sexes sit separately[4]. We distributed all the 24 notebooks in which six of the stained notebooks were among boys and the other 6 among girls. We asked the children to open their notebooks and whoever had his or her notebook stained, we listed them for the FGD a week after at the beginning of July 2003. The caregivers of the 12 children took part in the caregivers FGD.

3.1.6 **Researcher blinding**

We blinded the research assistants to each the participant's group to avoid biasing their scoring. As children knew the group they belonged to, they were not blinded, and we also recognized a potential Hawthorne effect (Wickström & Bendix, 2000) on participants undergoing the study. Therefore, this trial was "single blind"

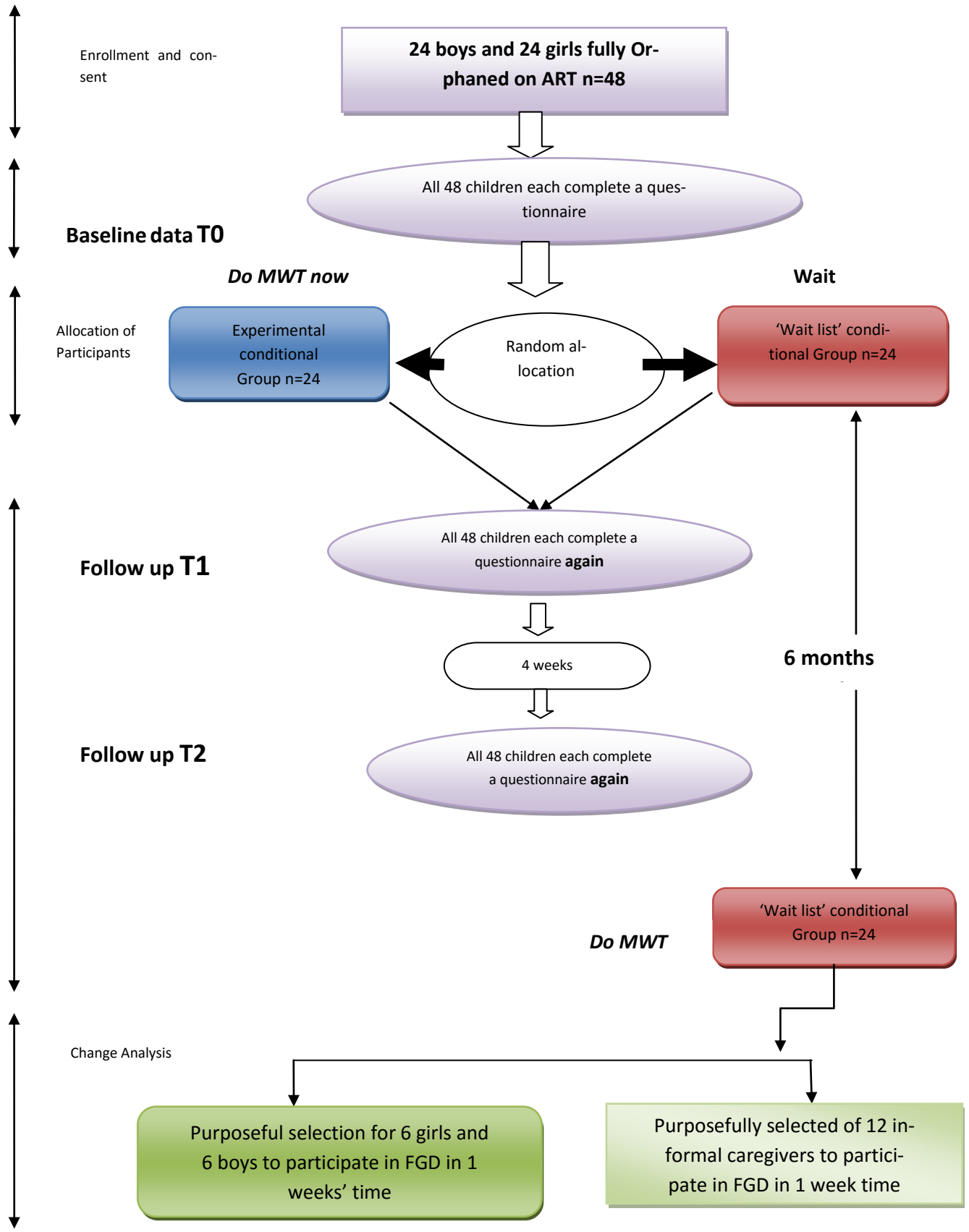
[4] In many African settings, there is a tendency of male children to spend most of their time with male adults and the girls with female adults. This justifies the gender roles that the two take up since childhood and become very visible during adolescence. With the coming in of Islam and Arabic culture, this separation of male and females sex and gender role become very profound. For example, in schools those are boys or girls in Islamic and even some, Christian schools. In Mosques, females and male sit separately. PASADA is in Dar-Es-Salaam, a city that is in the coastal area of the Indian Ocean. The Arabic/Islamic culture is very dominant in which female and male sexes should almost all the time do their work and live separately.

3.1.7 Collection of quantitative and qualitative data

3.1.7.1 Quantitative data through questionnaires

The experimental and 'wait list' groups at the beginning went through individual investigator administered questionnaires to collect baseline (T0) information; physical and psychosocial state, including some socio-demographic, bereavement and funeral information, education, kind of informal care givers (education, sex, age), religion, living in squatters or planned location, district, number of households as indicated in each child's file. Information on bereavement included date of death of parents. The MWT for the two groups took place at a 6 months interval beginning with the experimental followed by the 'wait list' groups. Following completion of the intervention (group 1) all participants (intervention and wait list) participated in a second round of data collection (T1), and then after a further month the third round of data collection (T2). The wait list group then received the intervention. Figure 3-1 below provides the details:

Figure 3-1 Trial flow chart



3.1.7.2 Qualitative data through Focus Group Discussions

We incorporated FGD in this study because we needed more insights from the participant. Holsman well expressed this as shown in figure 3-2 below:

Figure 3-2 Importance of FGD to this study

> *"Focus groups do lead to important insights about topics and allow the facilitator to probe a group's thinking on matters both scripted and that arise spontaneously through conversation. This feature makes it a more flexible tool than quantitative surveys. Focus groups are also advantageous when compared with conducting one-on-one interviews because they allow participants to feed off of one another's ideas and spark thoughts that may not have been captured in isolation"*(Holsman, 2002)

We did two FGD whose aim was to have some personal experiential information of the MWT interventions from both the caregivers and the children hence given them the opportunity to give us some suggestions to improve MWT intervention. We generally wanted to gather information of how both the children and the caregivers felt about the process. We however realized that the children as direct participants in the MWT could have different information about their experience compared to that of their caregivers who only participated in the FGD. It is for this reason the two groups had different sets of semi-structured questions to guide the FGD process. Table 3-3 below provides the details

Table 3-3 Focus Group Discussion Questions

No	Questions for Children	Questions for Caregivers
1	Can you tell me what you remember about the group, what did you do there?	How did you feel about the child attending the group? Did you have any concerns?
2	What did you enjoy? Why?	Did the child talk to you about the group and what happened? What did they tell you?
3	If we did it differently, what should we change?	Did they tell you if they enjoyed it, if so what did they like?
4	Has the group helped you in any way, what why?	Do you feel it helped the child, if so why?
5	Was there anything that was unhelpful?	Do you think it was unhelpful in any way?
6	Who do you think the group would be good for?	Was it easy to arrange for the child to attend; is there anything we could do to make it easier to attend?
7	Was it the right length, was a week good? And was it the right number of children?	What do you think a group could offer children that would be helpful?
8	What else would you like to say about the group?	

The two FGD were done a week after the wait list group intervention of MWT on 27 June 2013.We did this to maximize attendance of both the children and the caregivers. We run the FGD simultaneously to prevent any confounding if we did the two at different periods. We used Semi-

structured interview Swahili translated questions. We had consultations with Swahili speakers, and we used the *Tasisi ya Uchanguzi wa Kiswahili (TUKI) English-Swahili 3rd Dictionary*[5] in many cases to ensure better fidelity in translation. Three research assistants facilitated the two FGD. One of the research assistants was a moderator while the other one was a rapporteur. The third research assistant operated and recorded the discussions on a digital recorder. We wrote each participant's contribution against a unique ID number.

3.1.8 Measures and endpoints

Psychological and sociological wellbeing of patients is one of the four multi-dimensions of care in palliative care, which includes physical and spiritual wellbeing of the patients (Harding et al. 2010). With MWT aimed at improving the psychological and Sociological (Psychosocial) wellbeing of the patients, the trial used four tools that measure psychosocial wellbeing of the patients. The four tools helped in checking and balancing the psychosocial outcome of MWT of children at PASADA and augmented ART medical care in palliative care. Below are the four (4) measuring tools used:

- Brief Symptom Inventory (BSI)
- Rosenburg Self-Esteem Scale (RSES)
- Goodman's Strength and Difficulties Questionnaire (SDQ)
- Self-esteem Questionnaire for Children (SEQC) 14-Item Likert scale

We administered the measures at baseline (T0), immediately following the intervention (T1) and at one month (T2). All those tools, but the BSI and RSES have been validated in Africa and below are their details.

3.1.8.1 The Brief Symptom Inventory

This tool is used in palliative care for different patients including those with AIDS (Breitbart et al., 1996) . It helps the child to examine what he or she feels about his or her body, social interaction with people and some decision made in different situations. Figure-3 shows how BSI is used:

Figure 3-3 The Brief Symptom Inventory (BSI)

The Brief Symptom Inventory is a 53-item self-report symptom inventory designed to reflect the psychological symptom patterns of psychiatric and medical patients and non-patients. This inventory reports, profiles of nine primary symptom dimensions and three global indices of distress (Derogatis, 1993).

SOM – Somatization,
O-C - Obsessive-Compulsive,

[5] Institute of Kiswahili Research University of Dar-Es-Salaam

I-S - Interpersonal Sensitivity
DEP – Depression
ANX – Anxiety,
HOS – Hostility,
PHOB - Phobic Anxiety
PAR - Paranoid Ideation
PSY – Psychoticism

Global Indices
GSI- Global Severity Index, Helps measure overall psychological distress level
PSDI - Positive Symptom Distress Index, Helps measure the intensity of symptoms
PST - Positive Symptom Total

Key features:
The BSI test is brief and requires only 8-10 minutes to complete, making it well-suited for repeated administrations over time to evaluate patient progress.
The BSI instrument provides an overview of a patient's symptoms and their intensity at a specific point in time.
The Global Severity Index (GSI) is designed to help quantify a patient's severity-of- illness and provides a single composite score for measuring the outcome of a treatment program based on reducing symptom severity.
The reliability, validity, and utility of the BSI instrument have been tested in more than 400 research studies.

The BSI was developed from its longer parent instrument, the SCL-90-R, and psychometric evaluation reveals it to be an acceptable short alternative to the complete scale. Both test--retest and internal consistency reliabilities are shown to be very good for the primary symptom dimensions of the BSI, and its correlations with the comparable dimensions of the SCL-90-R are quite high. In terms of validation, high convergence between BSI scales and like dimensions of the MMPI provide good evidence of convergent validity, and factor analytic studies of the internal structure of the scale contribute evidence of construct validity. Several criterion-oriented validity studies have also been completed with this instrument. Answers are on a 5-point scale, from 0 = "not at all", to 4 = "extremely". The BSI also has high internal consistency (Cronbach's alpha: 0.71-0.85), test retest reliability, and convergent, discriminant, and construct validity.(Leonard R. Derogatis, 1993)

3.1.8.2 Rosenberg Self-Esteem Scale 1965 (RSES)

This tool measures a variety of different aspects of ordinary life of children. The questions in this tool ask the child's ability to do different activities in different environments including school and ability to take initiative in difficult circumstances. Though this tool has not yet been validated in Africa, but widely used in palliative care, Mueller and others used it in their study on adolescents and it proved very effective. We also found it extremely user friendly since it does not require a lot of time and the questions are very clear. "*Alpha reliabilities for this scale have been previously reported between 0.72 and 0.90"*(Mueller et al., 2011). Table 3-4 below provides the details:

Figure 3-4 The Rosenberg Self-Esteem Scale 1965

The RSES is ten item Likert scales with items answered on a four-point scale - from strongly agree to strongly disagree. The original sample for which the scale was developed consisted of 5,024 High School Juniors and seniors from 10 randomly selected schools in New York State. Instructions: ... If you strongly agree, circle SA. If you agree with the statement, circle A. If you disagree, circle D. If you strongly disagree, circle SD. On the whole, I am satisfied with myself, At times, I think I am no good at all, I feel that I have a number of good qualities, I am able to do things as well as most other people, I feel I do not have much to be proud of, I certainly feel useless at times, I feel that I'm a person of worth, at least on an equal plane with others, I wish I could have more respect for myself, All in all, I am inclined to feel that I am a failure, I take a positive attitude toward myself, Scoring: SA=3, A=2, D=1, SD=0. Items with an asterisk are reverse scored, that is, SA=0, A=1, D=2, SD=3 Sum the scores for the 10 items. (Votano, Parham & Hall, 2004)

3.1.8.3 Goodman's Strength and Difficulties Questionnaire (SDQ)

This tool is already used in palliative care to support children and adolescents and their families (Kühne et al., 2012) *"The SDQ (Goodman, 1997) is one of the most commonly used measures of mental health in children and young people and has been translated into more than forty languages"* (Cefai et al., 2011). Figure 3-5 below provides the details:

Figure 3-5 Goodman's SDQ

The 25 items each load onto one of five subscales: Emotional Symptoms, Conduct Problems, Hyperactivity, Peer problems and Prosocial Behaviour. The SDQ is specifically designed for children of the appropriate age group to this study and has been extensively validated in several languages (including African languages) [There is even a Swahili vision(Robert Goodman 2005)] and in both developed and developing countries… The Youth self-report version used in this study has been validated for self-completion and for adolescent populations and has a reported alpha coefficient of 0.82(Mueller et al., 2011)

3.1.8.4 Self-efficacy Questionnaire for Children

Understanding the Self-efficacy of patients is a very important requirement in Palliative Care assessment. There are however many different tools used to measure Self-efficacy. We measured Self-efficacy using the SEQC—a 14-item Likert scale. All the 14 questions in which the child is examined to see how he or she could do things differently or better (Nicole & Barrachit, 2009), are very positive and they all begin with '*How well*…?' The child is guided to rank him or herself from '1' to '5'. Each question has five spaces in which the children or the interviewer is able to tick (√) or cross (X). Ticking or crossing '1' entails very low self-efficacy and '5' very high in each question "*The validity has been internationally demonstrated …The emotional and social self-efficacy domains were used. Crohnbach's alpha for the adapted scale with this sample was 0.758"* (Mueller et al., 2011).

3.1.9 **Statistical Analysis**

We analyzed the data to determine:

- Description of the sample in terms of demography, prevalence and intensity of the problems at baseline
- Baseline equivalence of the 2 groups
- Plot the two groups by each outcome measure over time
- Attrition

For quantitative data, we compared the scores at each time-point using parametric and non-parametric comparison of means and ANCOVA to take account of covariance. We subjected Qualitative interviews (FGD) to basic thematic analysis to determine the experience of the intervention and

how it may be refined. During this statistical analysis process, we performed 'Intention to Treat Analysis' and we analyzed each child in his or her randomized groups.

3.1.10 **Trial timetable (Duration and participation)**

The study duration was 24 months and the maximum duration of participation of children and their caregivers was 6 months. Table 3-3 below has the details:

Table 3-4 Trial Time frame of Activities

No.	Activity	Responsible	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
1	Working on the research protocol, ethical submission, meeting with PSS facilitators and training of Research Assistants	PI	■	■	■	■	■	■																		
2	Recruiting participants and will be made possible since the children come for different activities at PASADA								■	■	■															
3	Baseline data questionnaire for each of 48 participants	PI and RA										■	■	■	■											
4	Intervention experimental condition group MWT only	F and PI														■										
5	Questionnaire for all 48 participants after 1 week																■	■								
6	Questionnaire for all 48 participants after further 4 weeks	F and PI																	■							
7	Intervention for the wait List group after 1 week																			■						
8	Separate FGD for 12 children and informal caregivers																				■					
9	Primary analysis and writing the reporting	PI																				■	■	■	■	■

KEY

PI = Principal Investigator

RA= Research Assistant

F=Facilitator

3.1.11 **Data and Trial management**

PASADA is one of the major organizations that are working with Repssi in mainstreaming PSS in different areas especially in health care. Therefore, the trial benefited from an FBO that apart

from caring for adults has an established OVC Department and recently introduced the Pediatric unit in the Medical Department. PASADA is one of the Beacon centers for excellence in Palliative Care in Africa –The one-stop-shop approach to providing care—is providing Holistic care for people directly or indirectly affected by HIV and AIDS since 1992. The Principal Investigator (Elvis Joseph Miti) took advantage of this Palliative Care environment to ensure the trial is according to the framework of PASADA's aim and objectives. As regards to data storage, every child cared for by PASADA has a file and a corresponding number (OVC and/or CTC number). These files are only accessible to staff of PASADA in a respective department and other concern HCP.

For the purposes of this study, we allocated each participant a new unique study ID. Their names were stored separately from all data such as completed questionnaires. Every page of the questionnaires had a unique ID of a particular participant. Other data, such as electronically recorded FGD are stored in the lockers of the OVC Department Director's office. We received ethical approval from UCT (where the PI is studying for an MPhil in Palliative Care) and NIMRI (Tanzania) to manage this data.

3.2 Ethical Issues

3.2.1 PASADA and MWT for children

All the 48 children in the study were PASADA patients. The organization, therefore found this study as an audit of one of its health services. To ensure the number of the children who attend MWT is manageable, there are two sessions of MWT at PASADA in January and June. There was therefore a natural environment for a first group to attend and a wait list. Only competent children between the ages of 14 and 18 participated in the study. Informed written assent and consent of the children and from their informal caregivers respectively were required for participation. Each child had to get permission from school for 5 days to attend the seminar. The venue for the seminar has over the years proven as safe place for the children. All the facilitators of MWT have signed a Children protection agreement, and therefore the children were free from possible abuse from the facilitators.

The children and their caregivers did not incur any cost during the seminars. The tools were available and well used in this population. To manage possible distress during the seminars, we used Repssi manuals on MWT. We considered privacy and confidentiality using unique code numbers of study participants in presenting quotations for qualitative data. We clearly informed the participants in FGD about the need for confidentiality even though we could not guarantee this because of the nature of FGD. The participants were informed that while sharing their experiences or views was very much encouraged during the FGD, they were not compelled to share.

3.2.2 **Institutional ethical clearance from trial partners**

PASADA officially allowed the PI to integrate MWT into the trial on 4th June 2012 and Repssi gave permission to use the manuals for Memory Work and other documents for citation 2nd March 2012. Ethical approval was submitted to Human Research Ethics Committee (HREC) of UCT. The trial was formally approved on the 24thOctober 2012 (HREC REF; 284/2012). We also submitted ethical approval to the National Institutes for Medical Research Tanzania (NIMR). Ethical approval was released on the 28thFebruary[6] 2013 (NIMR/HQ/R.8a/Vol.IX/1481) for this trial to take place in Tanzania. See appendices for details.

3.3 **Demographic questionnaire and translation**

To establish the protective and risk factors that would influence children's response to MWT, socio-demographic (Mueller et al., 2011) information of the family, including the location, and education was incorporated at the beginning of the interviews. It was, however, not possible to have information about the viral load of each participant because PASADA does not do viral load tests. It is also very expensive at more than USD 50 per person and only 10 patients go for viral test every year according to PASADA budget. We did forward and backward translation into Swahili to all the tools, but the SDQ since it is already officially translated. The tools were researcher-administered.

[6] NB: Normally the first group receives intervention in January, to facilitate this NIMR allowed the PI to continue with the trial since the approval letter would be late by 1-month deal to circumstances beyond their control.

4 CHAPTER FOUR

4.1 Data Presentation, analysis, interpretation, and Discussion

4.1.1 Demography of the participants

Table 4-1 below provides details of the distribution of the participants in the trial:

Table 4-1 Participants of the trial

ID NO.	GROUP (1 Experimental 2 Control)	SEX	Age	Education of child	District	Death of father	Death of Mother	No. Household	Head of Household	Education of caregiver	Employment	CD4
1	2	M	17	Form2	Kinondoni	Unknown	2000	2	Uncle	None	none	705
2	1	F	15	Vocational training	Temeke	2012	Don't know	8	Aunt	Primary	Microbusiness	166
3	1	F	17	Form2	Kinondoni	Unknown	1997	5	Aunt	Unknown	none	260
4	2	M	17	Form4	Temeke	2002	2006	5	Grandpa	Primary	employed	250
5	1	M	17	Vocational training	Kinondoni	2010	2000	4	CHH	Secondary	Microbusiness	432
6	1	M	16	Form4	Temeke	2003	2000	6	Aunt	Primary	Microbusiness	650
7	1	F	14	Form2	Kinondoni	2000	2006	6	Aunt	Primary	Microbusiness	360
8	2	M	18	Form2	Temeke	2005	2002	6	Aunt	None	employed	400
9	1	F	15	Std7	Kinondoni	1997	2007	3	Aunt	Primary	Microbusiness	797
10	2	F	14	Std7	Ilala	2007	2003	5	CHH	Primary	Microbusiness	200
11	2	F	17	Form3	Kinondoni	Don't know	Don't know	12	Grandma	Vocational train-ing	Peasant	120
12	1	M	18	Form3	Kinondoni	2003	2002	17	Aunt	Primary	Microbusiness	299
13	2	F	16	Form4	Kinondoni	Don't know	2004	5	Grandpa	Secondary	employed	186
14	2	F	17	Form2	Temeke	Don't know	2000	6	Uncle	Primary	Microbusiness	380
15	1	F	14	Form1	Temeke	2000	2006	19	Aunt	Unknown	none	341
16	1	M	17	Form3	Ilala	2011	2007	7	Uncle	Secondary	Microbusiness	221
17	2	M	17	Std6	Rufigi	1995	2007	5	Grandma	None	Peasant	300
18	1	M	18	Form4	Temeke	Not sure	2004	4	Grandma	Primary	none	576
19	2	F	14	Form1	Temeke	2004	2005	2	Grandma	Primary	Microbusiness	259
20	1	M	18	Form2	Temeke	2004	1993	8	Uncle	Secondary	Microbusiness	237
21	2	F	15	Std7	Kinondoni	Unknown	2009	4	Grandma	Primary	none	150
22	1	M	15	Std7	Ilala	1999	2002	3	Grandpa	Secondary	employed	187
23	2	M	14	Form1	Kinondoni	2003	2004	3	Sister(Adult)	Secondary	none	278
24	1	F	14	Form1	Kinondoni	2010	Unknown	3	Aunt	Secondary	none	465
25	2	M	14	Form1	Kinondoni	Unknown	2009	6	Uncle	Not sure	none	395
26	1	F	14	Not at school	Temeke	1998	1999	9	Sister(Adult)	Primary	Microbusiness	372
27	1	F	14	Std4	Ilala	2000	2007	3	CHH	Vocational train-ing	none	463

28	2	M	15	Std7	Kinondoni	1998	1997	6	Grandma	Primary	Microbusiness	294
29	1	F	16	Form2	Ilala	2007	2002	3	Aunt	Secondary	employed	970
30	1	F	17	Form3	Temeke	2010	2004	3	Aunt	Secondary	Microbusiness	531
31	2	F	14	Std6	Temeke	Don't know	Don't know	8	Brother in law	Unknown	employed	192
32	2	F	18	Vocational training	Ilala	2004	2006	9	Grandpa	None	none	300
33	1	M	15	Form1	Ilala	2010	2002		Grandma	Vocational training	none	440
34	1	M	14	Std7	Temeke	Unknown	Unknown	2	Aunt	Secondary	none	391
35	2	M	15	Std7	Temeke	2000	1998	15	Aunt	Primary	Peasant	219
36	2	F	14	Std7	Temeke	2000	2000	6	Grandma	Primary	Microbusiness	2000
37	2	M	18	Form4	Temeke	1997	1997	4	Uncle	Higher learning	Microbusiness	262
38	1	M	14	Form2	Kinondoni	2004	Not sure	6	Brother in law	Not sure	employed	652
39	1	F	15	Form2	Kinondoni	1999	2000	6	Grandma	Primary	employed	744
40	1	M	15	Form2	Temeke	Unknown	Unknown	2	Grandma	Primary	none	433
41	1	Fe	15	Form1	Temeke	2002	2002	19	Aunt	Unknown	none	951
42	2	M	16	Form3	Temeke	1996	2006	5	Aunt	Secondary	employed	434
43	2	F	18	Std7	Temeke	Unknown	2003		Grandma	None	none	269
44	2	M	15	Form1	Temeke	Don't know	Don't know	4	Grandma	None	Peasant	186
45	1	M	17	Form1	Temeke	2005	1991	1	Aunt	Not sure	Microbusiness	253
46	2	M	15	Std5	Temeke	1999	2008	9	Uncle	Vocational training	employed	35
47	2	F	15	Form1	Kinondoni	2000	2002	6	Aunt	Primary	none	406
48	2	F	15	Std7	Temeke	Don't know	Don't know		Aunt	Primary	Unknown	740

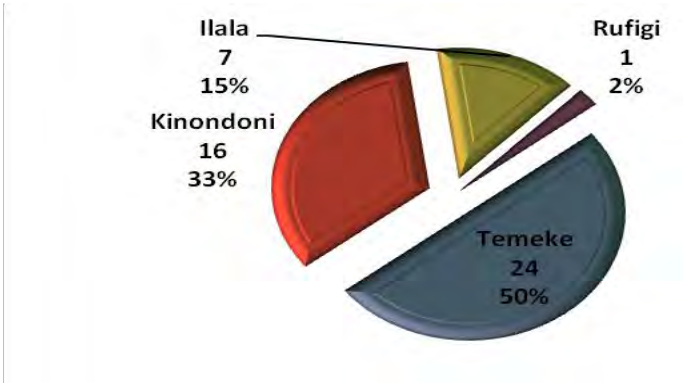
Source: Data base RCTII Memory Work PASADA

4.1.2 **Where the participants live**

The figure 4-1 below shows that 50% (24) of the children came from Temeke. This is not surprising since PASADA headquarters is located in the same place and in fact, Temeke is the poorest district in Dar-Es-Salaam, which has an HIV rate of 9.5%.[7] It is one of the most affected districts. Equally affected by HIV and AIDS is Kinondoni where most of the middle class and the rich live. The reason why there is only 33% (16) participation is that it is more than 20 km from PASADA. This is followed by Ilala district with only 15% (7) and this is because the district has the most health centers and relatively far from PASADA. Not surprising that we had only 2% (1) from Rufiji since this place is in fact in another district about 160 km from PASADA even though it is part of the catchment area. It is however very interesting to realize that all the districts in Dar-Es-Salaam and coastal region (Rufiji) were represented. Figure 4-1 below provides the details:

[7] Source: National Bureau of Statistics (NBS) and ORC Macro. 2008.
Tanzania HIV and Malaria Indicator Survey 2007-8. Dar es Salaam, Tanzania.

Figure 4-1 Where the children Come from

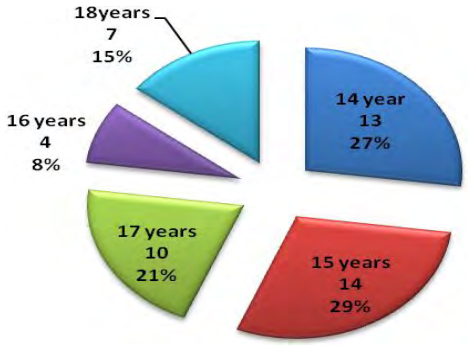


Source: Data base RCTII Memory Work PASADA

4.1.3 Distribution of ages

Fourteen children aged 15 represented 29% of all the participants in the trial. This was closely followed by those aged 14 years of age at 27%. Only four children were 18 years of age at 8%. Among the participants were 10 children who were 17 years of age at 21%. Seven percent (15) of participants turned 18[8] years of age during the course of the trial and continued receiving care and treatment in the OVC department and Paediatric unit. Figure 4-2 below provides the details:

Figure 4-2 Distribution of participants



Source: Data base RCTII Memory Work PASADA

[8] In Tanzania like many other developing countries, there are a good number of children who do not have birth certificates. It is therefore very difficult to determine the exact ages of most children. In PASADA's mission to ensure most children have access to treatment and care, different efforts are under-way to ensure each child has a birth certificate. In the process, however it is very difficult to determine a child who is just below 18 years. This is even worse when working in a program that takes a long time that has an age limit. It is for this reason children who are estimated to turn 18 and would be during the course of the trial were admitted.

4.2 Experimental and Control (Wait list) Groups analysis

4.2.1 Different scores of the Outcome tools at each time point (T0, T1, and T2)

Table 4-2 Scores of the Outcome tools at T0, T1 and T2

	Time 0 (T0)				Time 1 (T1)		Time 2 (T2)	
Characteristics	**Whole sample**	**Control (wait list)**	**Intervention**	**Comparison**	**Group effect**	**R^2**	**Group effect**	**R^2**
Age mean (SD)	15.7 (1.5)	15.8	15.6	T=-0.395 P=0.695				
Gender	Male n=24 Female n=24	Male n=12 Female n=12	Male n=12 Female n=12	X^2<0.000 P=1.0				
Education		N/A	N/A	N/A				
Number of household mean (SD)	6.0 (4.2)	5.8	6.3	T=0.343 P=0.703				
Head of household		N/A	N/A	N/A				
CD4 mean (SD)	382.3 (213.8)	298.3	466.3	T=2.933 P=0.005				
Total Brief Symptom Inventory score	78.7	93.9	63.4	T=-2.404 P=0.021	P<0.001* B=44.985 (95%CI=25.5, 64.4)	53%	P=0.001* B=46.668 (95%CI=21.541, 71.835)	45%
Total Rosen-berg self-esteem scale	12.4	12.1	12.8	T=0.725 P=0.472	P=0.109 B=-1.922 (95%CI=-4.292, 0.448)	9%	P<0.001* B=-4.392 (95%CI=-6.738, -2.046)	30%
Goodman's Strength and Difficulties Questionnaire:								
Hyperactivity scale	3.4	3.2	3.5	T=0.445 P=0.658	P=0.069^ B=1.398 (95% CI -0.113, 2.909)	10%	P=0.003* B=2.146 (95% CI -0.786, 3.507)	21%
Emotional scale	4.2	4.6	3.7	T=-1.394 P=0.170	P=0.090^ B=1.635 (95% CI -0.267, 3.537)	7%	P=0.080^ B=1.618 (95% CI -0.198, 3.435)	8%
Conduct scale	3.4	3.3	3.4	T=0.092 P=0.927	P=0.012* B=1.680 (95% CI=0.390, 2.971)	10%	P=0.310 B=0.745 (95% CI=-0.715, 2.204)	3%
Peer problems	3.6	3.6	3.5	T=-0.210 P=0.835	P=0.738 B=0.097 (95% CI -0.485, 0.680)	0.6%	P=0.294 B=0.708 (95% CI -0.635, 2.052)	4%
Prosocial	7.8	7.6	8.1	T=1.102 P=0.276	P=0.941 B=-0.068 (95% CI -1.884, 1.749)	2%	P=0.164 B=-1.012 (95% CI -2.453, 0.429)	5%
Total diffi-culties	14.5	14.9	14.0	T=-0.625 P=0.535	P=0.010* B=4.811 (95% CI 1.226, 8.396)	15%	P=0.002* B=5.218 (95% CI 1.960, 8.476)	20%
Self-Efficacy Questionnaire for Children:								
Social scale	25.1	25.25	25.0	P=0.857 T=-0.181	P=0.015* B=-4.539 (95% CI -8.161, -0.918)	18%	P=<0.001* B=-7.791 (95% CI -11.320, -4.262)	38%
Emotional scale	21.4	22.0	21.0	P=0.389 T=-0.869	P=0.002* B=-5.803 (95% CI -9.434, 2.171)	23%	P=<0.001* B=-9.007 (95% CI -12.032, -5.983)	46%

Source: Data base RCTII Memory work PASADA ***Significant result ^Trend to significance**

NB: We could not compare *"education level"* and *"head of household"* because both could not be expressed numerically or by any standard unit.

4.2.2 Participants and demography at T0

Randomization was successful as seen from table 4-3 and the two groups were comparable:

Table 4-3 Sample characteristics

Characteristics				
	Whole sample	**Control**	**Intervention**	**Comparison**
Age mean (SD)	15.7 (1.5)	15.8	15.6	T=-0.395 P=0.695
Gender	Male n=24 Female n=24	Male n=12 Female n=12	Male n=12 Female n=12	X^2<0.000 P=1.0
Education		N/A	N/A	N/A
Number of household mean (SD)	6.0 (4.2)	5.8	6.3	T=0.343 P=0.703
Head of household		N/A	N/A	N/A
CD4 mean (SD)	382.3 (213.8)	298.3	466.3	T=2.933 P=0.005
Total Brief Symptom Inventory score	78.7	93.9	63.4	T=-2.404 P=0.021
Total Rosenberg self-esteem scale	12.4	12.1	12.8	T=0.725 P=0.472
Goodman's Strength and Difficulties Questionnaire:				
Hyperactivity scale	3.4	3.2	3.5	T=0.445 P=0.658
Emotional scale	4.2	4.6	3.7	T=-1.394 P=0.170
Conduct scale	3.4	3.3	3.4	T=0.092 P=0.927
Peer problems	3.6	3.6	3.5	T=-0.210 P=0.835
Prosocial	7.8	7.6	8.1	T=1.102 P=0.276
Total difficulties	14.5	14.9	14.0	T=-0.625 P=0.535
Self-Efficacy Questionnaire for Children:				
Social scale	25.1	25.25	25.0	P=0.857 T=-0.181
Emotional scale	21.4	22.0	21.0	P=0.389 T=-0.869

Source: Data base RCTII Memory work PASADA

The standard deviation (mean) age of the all participants was 15.7 (1.5) and the P value was less than 95% indicating that there was no major difference at baseline. We did notice that there was a difference between groups on CD4 count and we adjust for that. With respect to

baseline scores, there was a difference only for the BSI total score. *'Education'* and *'head of household'* was not applicable (NA) because there was no standard measure.

4.2.3 **Findings at the first follow up (T1)**

Baseline (T0) to T1 multivariate regression analyses with T1-T0 change score as dependent variable, controlled for CD4 count (and baseline score for BSI) and group as independent variable. Table 4-4 below provides the details:

Table 4-4 Findings at T1

	Group effect	**R^2**
Total Brief Symptom Inventory score	P<0.001* B=44.985 (95%CI=25.5, 64.4)	53%
Total Rosenberg self-esteem scale	P=0.109 B=-1.922 (95%CI=-4.292, 0.448)	9%
Goodman's Strength and Difficulties Questionnaire:		
Hyperactivity scale	P=0.069^ B=1.398 (95% CI -0.113, 2.909)	10%
Emotional scale	P=0.090^ B=1.635 (95% CI -0.267, 3.537)	7%
Conduct scale	P=0.012* B=1.680 (95% CI=0.390, 2.971)	10%
Peer problems	P=0.738 B=0.097 (95% CI -0.485, 0.680)	0.6%
Prosocial	P=0.941 B=-0.068 (95% CI -1.884, 1.749)	2%
Total difficulties	P=0.010* B=4.811 (95% CI 1.226, 8.396)	15%
Self-Efficacy Questionnaire for Children:		
Social scale	P=0.015* B=-4.539 (95% CI -8.161, -0.918)	18%
Emotional scale	P=0.002* B=-5.803 (95% CI -9.434, 2.171)	23%

Source: Data base RCTII Memory work PASADA *Significant result ^Trend to significance

4.2.4 **Findings at the second follow up (T2)**

Baseline (T0) to T2 multivariate regression analyses with T2-T0 change score as dependent variable, controlled for CD4 count (and baseline score for the BSI) and group as independent variable. Table 4-5 below provides the details of the findings:

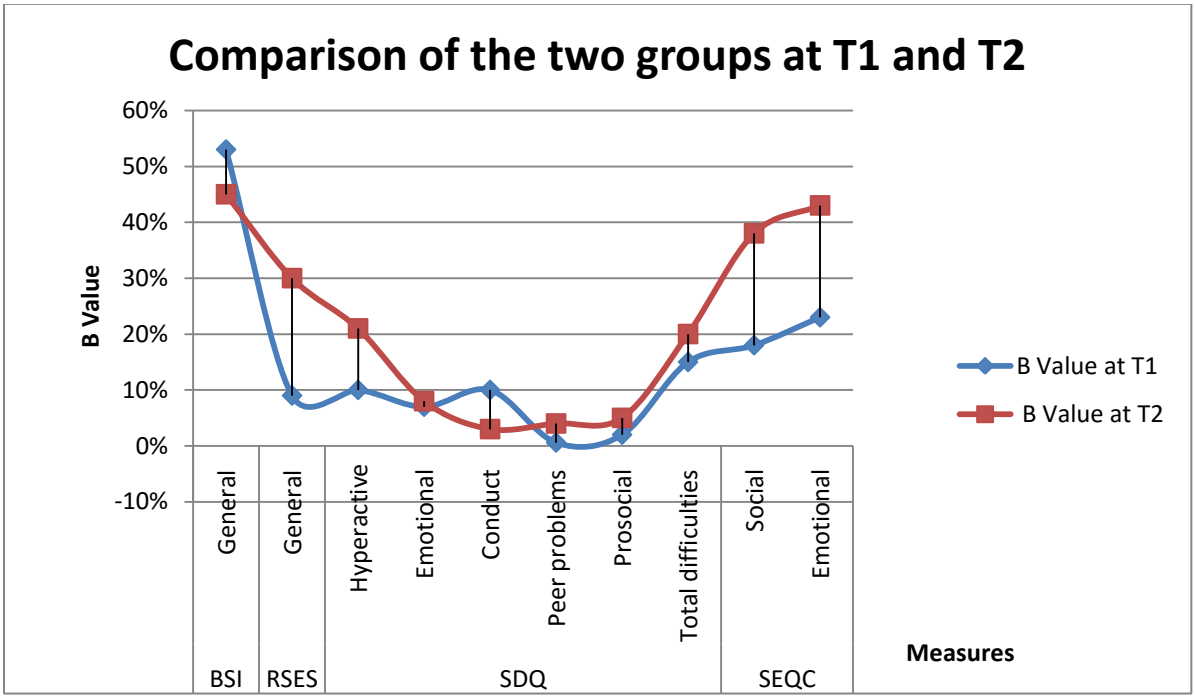
Table 4-5 Findings at T2

	Group effect	**R^2**
Total Brief Symptom Inventory score	P=0.001* B=46.668 (95%CI=21.541, 71.835)	45%
Total Rosenberg self-esteem scale	P<0.001* B=-4.392 (95%CI=-6.738, -2.046)	30%
Goodman's Strength and Difficulties Questionnaire:		
Hyperactivity scale	P=0.003* B=2.146 (95% CI -0.786, 3.507)	21%
Emotional scale	P=0.080^ B=1.618 (95% CI -0.198, 3.435)	8%
Conduct scale	P=0.310 B=0.745 (95% CI=-0.715, 2.204)	3%
Peer problems	P=0.294 B=0.708 (95% CI -0.635, 2.052)	4%
Prosocial	P=0.164 B=-1.012 (95% CI -2.453, 0.429)	5%
Total difficulties	P=0.002* B=5.218 (95% CI 1.960, 8.476)	20%
Self-Efficacy Questionnaire for Children:		
Social scale	P=<0.001* B=-7.791 (95% CI -11.320, -4.262)	38%
Emotional scale	P=<0.001* B=-9.007 (95% CI -12.032, -5.983)	46%

Source: Data base RCTII Memory work PASADA *Significant result ^Trend to significance

From tables 4-3 and 4-4 above, it is evident there was a difference between experimental and wait list groups in a number of outcomes. Importantly, this difference was also present at the second follow up and actually increased (i.e. More significant from the P value and the effect size, that is, the B value got bigger. The B value tells how the score changes when you go from group 1. That is, experimental to group 2 or wait list group. It says if you go from score 1 to score two, then the B is the effect on the score. For example B value for BSI at T1 was B=44.985 and at T2 it increased B=46.668. This means there was progress in the experimental than the wait list groups. Answering the research question No. 1, we can evidently say that there was no significant different before intervention between the experimental and wait lists groups (table 4-1), but there was a progressive significant difference at follow up T1 and T2 as the B value got bigger. Figure 4-3 below provides the graphic summary:

Figure 4-3 Comparison of the two groups at T1 and T2



Source: Data base RCTII Memory work PASADA

4.3 FGD FINDINGS

4.3.1 FGD Participants

Table 4-6 below provides the composition of the adolescents' group for FGD:

Table 4-6 Children Participants of FGD

ID NO.	Control Group	SEX	Age	Education of child	District	Death of father	Death of Mother	No. Household	Head of Household	Education of caregiver	Employment	CD4
4	2	Male	17	F4	Temeke	2002	2006	5	Grandpa	Primary	employed	250
8	2	Male	18	F2	Temeke	2005	2002	6	Aunt	None	employed	400
11	2	Female	17	F3	Kinondoni	Unknown	Unknown	12	Grandma	Vt	Peasant	120
14	2	Female	17	F2	Temeke	Unknown	2000	6	Uncle	Primary	Micro business	380
17	2	Male	17	S6	Rufigi	1995	2007	5	Grandma	None	Peasant	300
19	2	Female	14	F1	Temeke	2004	2005	2	Grandma	Primary	Micro business	259
21	2	Female	15	S7	Kinondoni	Unknown	2009	4	Grandma	Primary	none	150
25	2	Male	14	F1	Kinondoni	Unknown	2009	6	Uncle	Not sure	none	395
31	2	Female	14	S6	Temeke	Unknown	Unknown	8	Brother in law	Unknown	Unknown	192
37	2	Male	18	F4	Temeke	1997	1997	4	Uncle	Higher learning	Micro business	262
42	2	Male	16	F3	Temeke	1996	2006	5	Aunt	Secondary	employed	434
47	2	Female	15	F1	Kinondoni	2000	2002	6	Aunt	Primary	none	406

Source: Data base RCTII Memory Work PASADA

4.4 Children's FGD

4.4.1 What children remembered?

Discussing FGD questions 1 and 2, it shows how the children remembered the most important developments during the therapy. This may not be strange since it was just over one week since the waitlist group completed their MWT. The composition of the FGD members had also contributed to such a lively discussion. Adolescents with an average age of 16 years old made the group. The group process effect (members of the group developing unity and trust among each other) contributed a lot in creating a condition that enabled almost total participation. Generally, the children remembered a variety of activities during the MWT intervention. The children remembered very clear example of activities undertaken. They described specific activities as shown in table 4-7 below:

Table 4-7 What Children remembered from FGD

ID	What was remembered by children
4	*"I discussed a lot of ambitions. The facilitators helped me reflect about my life, I made a memory box and kept my late father's picture"*
8	*"I drew a dress that was given to me by my guardian, I remember I was very happy that day, I discovered the hero of my life and also discovered that I am a hero even though I am living with HIV and AIDS. Drawing the tree of life was a journey in my life. I had the opportunity to acknowledge the support I am receiving from different people in my life"*
11	*"I discovered the relatives who surround me, I discussed with my friends the different problems that I face, we exchanged our books and drew half of the faces, we ate good food, and we played games"*
14	*"I drew a picture of my worst moment 'my brother was very sick that day', I made a tree of life I and drew different people who are around me"*
17	*"We ate good food, I made a memory book, I put my mother's rosary in the memory box, I remember when my father died, and I discovered different way to deal with the challenges from what others said.*
19	*"We did the tree of life, we played games, I had a new name and I dedicated my book to my father"*
21	*"I made a memory box, I draw a picture of myself, and we made books using paper and threads"*
25	*"We discussed different events in our lives painful and joyous, I made my hero book, and we played a lot of games. I made different friends. The facilitator helped me improve my memory book"*
31	*"I ate good food, we played some games, we discussed many problems, I put my late father's picture in the box, I found a new name and meaning, I draw a picture of the clinic where I was admitted"*
37	*"I did a lot of drawing in my book, I drew the tree of life, I discussed my life with my friends, and the facilitators gave us a lot of work to do. I learnt some life skills. I met different friends. We were helped to make our own books using a hammer and thread and paper"*
42	*"There was a lot of work to do, I made my own book using thread and hammer, the facilitators told us to divide into pairs and discuss issues, I added on my life skills"*
47	*"The facilitator helped us build resilience. I discovered different resources that I have in my environment; we ate a lot of food".*

Source: Data base RCTII Memory work PASADA

Table 4-7 shows all the 12 participants in FGD had something to remember. This is very important since this reflects how the participants were interested in the MWT process. It is furthermore, important through this discussion; they revealed their personal issues as individuals living with HIV and members of their communities. This is very important because it is the very essences of PSS as participant ID No.8 puts it:

> *"I drew a dress that was given to me by my guardian, I remember I was very happy that day, I discovered the hero of my life and also discovered that I am a hero even though I am living with HIV and AIDS. Drawing the tree of life was a journey in my life. I had the opportunity to acknowledge the support I am receiving from different people in my life"*

It is also important to note the participants recalled very important activities specific of MWT. For example, the participants with ID numbers 14, 19 and 37 mentioned the Tree of Life. Participants ID numbers 8, 11, 19, 25, 37 and 42 remembered activities related to the hero and memory books. Participant No. 4, 17, 21 and 31 remembered the memory box. It was also interesting there were

some participants (11, 25, and 31) who appreciated other equally important activities such as games and food. Participants 11, 31 and 47 remembered eating very well during MWT. The participants (25, 37, 42 and 47) remembered the efforts made by the facilitators in MWT. Without underestimating what others remembered, participant ID no. 47 sums up the essence of what all the participants remembered:

"The facilitator helped us build resilience. I discovered different resources that I have in my environment;…"

4.4.2 What children liked?

MWT is meant to be a safe place for patients or clients. The whole process is geared to make the participants find most of the exercises very pleasing especially to children and young people. The participants indicated they enjoyed different activities during the intervention by pointing out specific exercises in MWT, the environment of the venue and facilitators as shown in table 4-8 below:

Table 4-8 What the children liked?

ID No.	What the children liked
8	*"The drawings I made and the tree of life and the ladder of ambitions.*
11	*"The tree of life, club of life I understand my surrounding and friends, met different friends and we played different games; "I had time to think about my past in an easier way"*
14	*"Facilitators, the environment, the food and drinks, drawings.*
17	*"I also enjoyed making the hero book and the memory box. I was very happy to be among friend. I liked the tree of life. Through the hero book, I remember I wrote who is my grandma, and so forth".*
19	*"Everything including the games and clubs of life, It was well organized and I am very thankful for all the efforts that were put in"*
21	*"I also liked the food and drinks and the discussions, we rarely have drinks at home"*
25	*"Making the memory box and the ladder of my ambitions, making toy cars using boxes and wires"*
31	*"I liked The food and the Club of life, I like chips and eggs "the food was well prepared".*
37	*"I liked Facilitators and discussing with friends, playing games, they played with us all the time.*
42	*"The environment and games, it was very quiet and most of the people there are very serious, "For the first time I realize that there are places in the world that are quiet and peaceful"*
47	*"Making memory box and dedication of the book to my caregiver, normally we buy those boxes for gift to others, I can make my own"*

Source: Data base RCTII Memory work PASADA

Table 4-8 shows the participants liked different activities during MWT. Like in table 4-7, the participants were very specific on different activities related to MWT process. To this question, however, the participants become clearer even though not all participants shared their experience as in the table 4-7. This is normal since in FGD, participants are free to listen or speak and this is important in PSS group process.

You will be interested to realize that participants ID no. 11 was very consistent in the way she participated in the discussion. The first question (table 4-7) about what she remembered, she said:

"I discovered the relatives who surround me, I discussed with my friends the different problems that I face, we exchanged our books and drew half of the faces, we ate good food, and we played games"

When she was asked what she liked in the second question, (4-8) she said:

"The tree of life, club of life, I understand my surrounding and friends, met different friends and we played different games; "I had time to think about my past in an easier way"

Looking at the two contributions of this 17 year old girls, it is evident she had a good synthesis of what was going on in her life during MWT. It is therefore clear that through the tree of life, she realized the different people in her community and realized how important it was for her to dwell on her experience. It is amazing to see how consistent she is on the importance of friends in her life. This is very important in MWT and in line with the change in the scores of the Outcome tools of the experimental group at T1 and T2.

4.4.3 What the children dislike

The children had quite some issues, which they disliked during the intervention. However, those issues provided some important feedback on how MWT would be improved as it is done at PASADA. The eight participants clearly provide some information on how we could consider involving the caregivers throughout the MWT and other requirements, even though this has some budgetary constraints as shown in table 4-9 below:

Table 4-9 What the children disliked

ID No.	What the children disliked
8	*"My grandmother is missing this important event"*
11	*"This activity was too short"*
14	*"Transport allowance should be increased since some of the children comes from very far"*
17	*"There are some participants who do not live very far from here. It would be unfair for all of us to be given a flat rate. Some of us come from very far"*
19	*"Food was not enough"*
21	*"Sometime I felt very congested because of the too many drawings I had to do"*
42	*"Some participants took a lot of time to finish using the hammers"*
47	*"caregiver did not attend "*

Source: Data base RCTII Memory work PASADA

The discussion on 'dislikes' had fewer contributions with only eight (8) out of (twelve) 12 participants contributing. The discussion however revealed some important issues on how MWT was important to participants and their families and how MWT could be improved at PASADA. As re-

gards to how MWT should have involved their families, participant ID no. 8 and 47 raised the issue of the participation of the grandmother and caregiver respectively taking part in MWT.

On one hand, the contribution of the children shows how they realized the importance and their families through MWT. This is a very important indicator in MWT since it shows how participants realized the importance of their families in building resilience in living with HIV. One the other hand however, it is a challenge to PASADA to see how they could integrate caregivers in the whole MWT process.

It was very important to note some participants did not like some logistic arrangements and participants ID no. 17 was very explicitly about that:

> *"There are some participants who do not live very far from here. It would be unfair for all of us to be given a flat rate. Some of us come from very far"*

4.4.4 What benefits the children experienced?

All the children found the group very helpful and gave different reasons. This included the realization of the importance of their caregivers, how living with AIDS is not so much a challenge than a problem, MWT is a support group and a source of self-esteem as shown in table 4-10 below:

Table 4-10 What benefits the children experienced

ID No.	*What benefits the children experienced*
4	*"I now understand how I could better live with my aunt and be a better child. I also would like to appreciate the support that I have received from my friends and the facilitators. My friends helped me understand how I am loved so much despite my HIV and AIDS status".*
8	*"I am confident in front of people, I know who should help me in my life and I am sure with what I am supposed to do as a person living with HIV and AIDS"*
11	*"I have developed a lot of confidence to explain different things. Club of life has helped me not to discriminate the different people around me.*
14	*"A hero book helped me to have the ability to live together with people and I know my responsibility and do better adherence to medication".*
17	*"The group was very friendly and helped me know my heroes and different obstacles in my life.*
19	*"I have learnt that living with HIV and AIDS is manageable and there are a lot of people in my family who are very helpful.*
21	*"It was easier for me to discuss my HIV and AIDS status without any fear and I built a lot of confidence in dealing with my status".*
25	*"I understand the meaning of my first names and the new one. I have new friends and the facilitators were very helpful indeed. I know the different people who help me when I am in problems. They will help me sail through even though I am living with AIDS"*
31	*"I learnt a lot from each one of them and I now realize the different talents that I have. "I thought I was the only one living with an old aunt"*
37	*" I should realize and acknowledge the different people who surround me and see how they are*

	helping me deal with my HIV and AIDS status"
42	*"I have develop confidence and realize living with HIV and AIDS is not a problem"*
47	*"The hero book helps the children stand firm".*

Source: Data base RCTII Memory work PASADA

The discussion on what the participants experienced provided the much need information on indicators of the MWT to children and young people. This discussion therefore, confirms the different significant changes that took place at different time points (T0, T1 and T2) in scores of the Outcome tools. It is therefore very interesting that all the 12 participants shared their experiences for it gave a whole picture of all the participants benefiting from MWT. It was also very important to realize that the participants were very specific in the way the MWT helped them build resilience in the face of HIV and AIDS.

Seven (7) participants (4, 8, 19, 21, 25, 37 and 42) specifically shared that they benefited so much and became "better" HIV and AIDS patients. Participant ID no.4 provided a powerful experience:

> *"I now understand how I could better live with my aunt and be a better child. I also would like to appreciate the support that I have received from my friends and the facilitators. My friends helped me understand how I am loved so much despite my HIV and AIDS status".*

Participant ID no. 19 made a concise observation of improved resilience against HIV and AIDS when he shared:

> *"I have learnt that living with HIV and AIDS is manageable and there are a lot of people in my family who are very helpful."*

Those experiences are very much in line with the changes indicated in the different Outcome tools for the Experimental group in which for example their Self-esteem and Self-efficacy improved significantly over a period of 4 months

4.4.5 **Things that were unhelpful**

Seven participants indicated that everything was good in the group, but four participants indicated there were some fundamental aftermath challenges in the outcome of MWT especially to children who came from very poor families without good shelter. Establishing material items that would better help children effectively benefit from their memories may require better *'stores'* and *'weather'*, otherwise keeping them safe and updated requires even more efforts than the MWT process itself. One child reflected the drawback related to interest in drawing and the mental and

physical ability that may be required in MWT as practiced at PASADA. Table 4-11 below provides some details:

Table 4-11 Things that were not helpful

ID No.	Things that were unhelpful
25	*"I do not have a place to keep the memory box"*
21	*"During the last floods, I lost most of my souvenirs including my parent's picture.*
19	*"I do not have important things to keep in that box. I will have to look for other souvenirs to put is that beautiful box"*
42	*"The memory box is not helpful since I have nowhere to keep it at home"*
47	*"Drawing is very difficult for me"*

Source: Data base RCTII Memory work PASADA

Despite this smaller number of participants (5) contributing to the discussion on things that were unhelpful, their discussion provided very important information on the types of materials that could best be used in MWT for poor communities. The demographic information shows that 24 (50%) of the participants came from Temeke (fig 4-1). This district is where most of the poor live in Dar-Es-Salaam Region(National Bureau of Statistics and Regional Commissioner's office, 2014). Most of the people in this area do not have proper housing and drainage system. Therefore, the concern reflected by participants ID no. 25, 21, 19 and 42 was varied.

This opened the door to reflect on how MWT could be been done using methods and materials that could withstand local social and economical situation of the participants. This is in fact a requirement of palliative care in which creativity is very important that captures the local environment of patients and their families

4.4.6 Other people who could benefit from this group

The children had different views, but they generally thought this group would be good for children on ART. The most remarkable observations, however, came from four participants who clearly prescribed MWT for all the children because of its empowering effect on AIDS patients and non-discriminatory reasons as shown in table 4-12 below:

Table 4-12 Other people who could benefit from this group

ID NO.	Other people who could benefit from this group
8	*"We should not discriminate children with AIDS. All should have MWT"*
11	*"To reduce stigma and this helps the children learn to live with others, all children got this exercise"*
17	*"You develop confidence and realize living with HIV and AIDS is not a problem and I would like*

	all children to have this feeling"
47	*"The hero book helps the children stand firm and it good for every child"*

Source: Data base RCTII Memory work PASADA

One of the biggest challenges in living with HIV and AIDS is stigmatization and discrimination. This is most of the time seen in two folds, which are self and social stigmatization and discrimination. The sharing from participants (8, 11, 17 and 47) indicates that MWT improved their personal and social interaction. The participants wanted all the children with HIV and AIDS receive MWT. For participants ID no. 8 and 11, leaving out other children with HIV and AIDS is discrimination and Stigmatization:

"We should not discriminate children with AIDS. All should have MWT"8

"To reduce stigma and this helps the children learn to live with others, all children got this exercise"11

Participant ID no. 17's sharing furthermore, is indicative of the significant change of the Outcome tools especially the Self-Efficacy Questionnaire for Children (SEQ)' Social Scale at T1 and T2 when he said:

"You develop confidence and realize living with HIV and AIDS is not a problem and I would like all children to have this feeling"

4.4.7 Length of time and the number of the participants

As regards to the length of the therapy, 10 children agreed that it was fine except 2 who disagreed with the rest by suggesting it should take more than 5 days. All the children, but one wanted the numbers of participants to increase. One of them indicated that this group should be comprised of 100 children. Two children suggested 35 and two children suggested 50, one child suggested 60 and the other 25. The other children did not suggest the exact number, but suggested the numbers should be increased. Throughout the discussion, however, there were some issues in which the participants passively indicated the duration and the numbers of children would be fitting. It however, appeared children realize this would be beneficial to a larger number of children. Table 4-13 below shows the details:

Table 4-13 Length of time and number of participants

ID No.	***Length of time***	*Number of participants*
4	*There is no problems with time*	*"There are many children who need this"*
8		*60 would be ok*
11		*It would be better to have 35 children*
14	*5 days is fine*	*"I wish all the member of my family could attend"*

17		*35 would be fine for me*
19	*'This exercise should take place every month..."*	*"More children should be involved"*
21	*It's ok*	*"The number should include more children"*
25		*I would suggest we have 50 children*
31	*"It should be more than two weeks"*	*"More children should attend"*
37	*Adding more time would mean less time for studies*	
42		*25 is good for me*
47		*We should have 100 participants*

Source: Data base RCTII Memory work PASADA

4.4.8 Other things which the children said about the group

Generally, the children were very happy with the group and wanted the group to continue. The children were thankful for taking part in MWT and the social relationship that developed be nurtured, and create possibilities of continuing with MWT and personal contact through mobile phones. Some children however, realized how MWT would negatively affect their secondary school studies if time were increased. Some children used this opportunity to express their spirituality and the transformation of their lives. Table 4-14 below provides some details:

Table 4-14 Other things which the children said about the group

ID No.	Other things which the children said about the group
4	*"I am very thankful to you for this group. We have become a family"*
8	*"I do not have much to say but please let's be faithful to each other"*
11	*"I am very thankful for giving me this opportunity to participate in this seminar"*
14	*"I have nothing to say but that was very good"*
17	*"I am not so happy that we are soon parting and hope we will be meeting frequently"*
19	*"I suggest that we have more days added",*
21	*'I am very thankful for the ideas and the time each one has spared here"*
25	*"I have enjoyed talking to my friends. They have been so friendly indeed"*
31	*"The seminar should continue and this helped me to build confidence and I am different from the past"*
37	*"I wish we could continue with the discussion but adding more time would compromise studies since some of us are in Form 4"*
42	*"I would advise all the participants exchange contacts so that we could continue with our group"*
47	*"I have learnt a lot from my friends and may God bless you forever"*

Source: Data base RCTII Memory work PASADA

When discussing the other things, which the children said about the group, it is interesting to conclude that all the participants were very positive about the group and MWT. One thing to note here however is that MWT helped the HIV and AIDS patients become 'better' patients as indicated by participants ID no. 31 this is in line with general changes at T1 and T2 of the Experimental group:

"The seminar should continue and this helped me to build confidence and I am different from the past"

4.5 Informal Caregivers' FGD

4.5.1 Caregivers' participants

All the 12 informal caregivers (C) who attended were grandmothers[9]. This may be contrary to the demographic information where only five grandmothers were heads of the households. The informal caregivers included aunties, uncles and brothers in law and grandfathers as shown in the demographic data. It is, however, a common place at PASADA when the informal caregivers are asked to come to PASADA—it is mostly grandmothers who come. One of the reasons is that the grandmothers are the *'in charge'* for most of the orphaned children who are on ART even when there are other young people who normally are the economical household heads in the family. This also means the consent and assent to attend the groups was done not by one individual in the family, but a common agreement of the whole family. We could therefore conclude that agreement by the whole family to allow the children to participate was one of the goals of care by the family members. This is typical of Palliative Care.

4.5.2 Caregivers' feeling and concerns about the children attending the group

In general, all but one informal caregiver, expressed feeling very happy to have their children participate in the group. Some informal caregivers were concern about child abuse, adherence to medication and bulling during the therapy. Most of the informal caregivers were satisfied, honoured, and happy and they viewed this, as an opportunity that their children should never miss. Below are their feelings and some concerns in table 4-15 below:

Table 4-15 Caregivers' feeling and concerns about the children attending the group

ID No.	*Feeling*	*Concerns*
C4	*"I felt very well and I wanted the children to continue staying there and I am very happy with what they learnt,*	*"I did not believe that we would not pay anything for this service".*
C8	*"I felt very honoured since the children were very happy with the group and the children liked every activity including recreation,*	*"I was concern if he would adhere to medication".*
C11	*"I am very satisfied with the seminar and I would like this seminar to continue.*	*"I was concerned about bulling and fighting among the children as said by one of the participants".*
C14		*"...but complained with transport money since they stay very far"*

[9] *'Many children who have lost one or both parents, live with their grandparents (53%), often very elderly'* (Pact Tanzania)

C17	*"I am very happy with the way he was treated despite being infected",*	*"Sometime his health is not so good to attend such an important activity"*
C19		*"I was not sure what exactly my grand-child would be learning. I though she will lose out on the studies".*
C21	*"I am very happy for the children and very happy too with the care"*	*"I was worried since I have never sent my child to such a seminar".*
C25	*I am very happy and I wish he could attend again and again";*	*"Just worried about child abuse and peer pressure".*
C31	*"I wondered if my child would learn anything in the group but it is interesting that he did very well. I am very happy and the whole family is too".*	*"As others have mentioned, I was worried about child abuse".*
C37	*"It is a blessing from God. I just cannot imagine how PASADA is working harder to ensure that our children live a happy life despite the many health challenges they face.*	*"I did not have any concern"*
C42	*"I was very happy to have my grandchild partici-pate"*	*"There are sometime when some peo-ple would indicate that it would be free but it turns out that you need to pay a certain amount".*
C47	*"My granddaughter would not have the chance to meet friends and learn a lot of things"*	*"I thought my child was too young to attend this session and I was not sure about his adherence to medication".*

Source: Data base RCTII Memory work PASADA

4.5.3 What the informal caregivers heard about the group from their children

All the informal caregivers reported grandchildren talking about what happened during the therapy. The informal caregivers revealed the different important exercises, which the children found very important as take-away. This included, among other things, their experience with the memory box and book and the tree of life. The children also informed their informal caregivers about the facilitators. The children also reported about the many drawings they made. The quotation in table 4-16 below provides some details:

Table 4-16 What the informal caregivers heard about the group from their children

ID No.	*What the informal caregivers heard about the group from their children*
C4	*"The child talked about learning of a tree of life. He said he was a hero"*
C8	*"He told me they had a lot of games and did a lot of drawing and painting. He showed me a book with a lot of drawings"*
C11	*"The facilitators were very helpful she said; they help me to understand my life and the im-portance of confidence in living with HIV and AIDS. She drew some ladder that was showing her ambitions".*
C14	*"My granddaughter showed a book of drawing she made about her life. She also introduced me to a beautiful box and she claimed she is the one who made it. I am very interested in the tree of life since she included me in the roots and the leaves"*

C17	*"The first participant mentioned something about the box. When my grandson arrived, I thought he had brought me a gift from PASADA but only to be informed that he had learnt how to care about his precious things such as his birthday card, the pictures of his parents and other things such as the cross and the rosary that his mother left".*
C19	*"My grandchild would like to go back, she said she met new friend and she would like her young sister to participate too. I would like to agree with other participants on the box and the tree. What I know about such boxes is that we make them so that we could carry some gifts for a wedding or send off party for example. This one was something else. My granddaughter asked me to give her some souvenirs from her late mother and father. Indeed, I had some problem as to where I could keep those important items. Here I am, she has somewhere to put them"*
C21	*"When I look at some of the things that she came with home, I discovered she had a box of some kind. It was good looking. Opening to see what was inside; I realize she had placed pictures of her parents and other souvenirs. She told me that she had learnt how to keep the important things and how to be a Hero and love her friends".*
C25	*"He generally remembered many activities such as the hero book and friends"*
C31	*"As mentioned by others, the children learnt a lot of things. They are very happy with the facilitators and the venue. My granddaughter indicated that the venue was very quiet and the attendants were good. She was particularly very happy with the hero book and the tree of life. She says she had the opportunity to think about her family and the different things they are doing to her".*
C37	*"He in the first place did not understand what the drawing of the tree meant. My grandchild said there were relatives and different people in life. He even wrote my names on the roots of the tree. As mentioned by other participant, he informed me he had learnt a lot of things and he showed me a box which he claimed he would put his precious things in"*
C42	*"As indicated by the other participants, the children enjoyed the food. I think he has put on some weight because he looks more bright than usual. He said the food was very nice, they had some drink and chicken and did a lot of drawing"*
C47	*"The facilitators were very welcoming and taught us a lot of things. I remember I made my own book using a hammer and nails, the child told me".*

Source: Data base RCTII Memory work PASADA

While the main aim of the FGD was to gather data of the experience and get suggestions for improvements of MWT from participants and their caregivers, the discussion of the caregivers on what their children and youths reported, is indicative of how MWT could improve communication and unity between the caregiver and the patients. This is evident in participants ID no. C19

> *"My grandchild would like to go back, she said she met new friend and she would like her young sister to participate too. I would like to agree with other participants on the box and the tree. What I know about such boxes is that we make them so that we could carry some gifts for a wedding or send off party for example. This one was something else. My granddaughter asked me to give her some souvenirs from her late mother and father. Indeed, I had some problem as to where I could keep those important items. Here I am, she has somewhere to put them"*

It is also interesting to realize that children and youths were able to report on major activities of MWT to their caregivers as reported by participant ID no C37.

> *"He in the first place did not understand what the drawing of the tree meant. My grandchild said there were relatives and different people in life. He even wrote my names on the roots of the tree. As men-*

tioned by other participant, he informed me he had learnt a lot of things and he showed me a box which he claimed he would put his precious things in"

It is therefore not surprising to see there was significant change in the scores of the Outcome tools in the experimental ground at T1 and T2 confirming that MWT has significant out comes on children and youths on ART at PASADA

4.5.4 What children enjoyed and informed their informal caregivers

The informal caregivers revealed children reporting on different developments during MWT, which their children enjoyed. The quotations in table 4-17 below provide some details:

Table 4-17 What children enjoyed and informed their informal caregivers

ID No.	*What children enjoyed and informed their informal caregivers*
C4	*"He liked the venue and he was happy to realize that he was not the only one living with HIV and AIDS. The child said he did not experience any stigma and discrimination for the first time"*
C8	*"Like the new names they gave themselves. He enjoyed fellow children calling him by the new name "LOVE"*
C11	*"They liked making new friends through the comments they wrote in their memory books"*
C14	*"They liked the facilitators and they paid a lot of attention to them even though they are living with HIV and AIDS"*
C17	*"They enjoyed the food and transport money"*
C19	*"My granddaughter as mentioned by others liked the facilitators and making the memory box"*
C21	*"I agree with the rest, the children liked the games, the foods and the drawings which they made"*
C25	*"The children liked the games and other recreational activities"*
C31	*"They liked the drawing and making the books"*
C37	*"They enjoyed the drawings and painting"*
C42	*"He thought he was the only one who was living with HIV and AIDS at his age. He said he made new friends"*
C47	*"They enjoyed making memory box"*

Source: Data base RCTII Memory work PASADA

Children reported realizing they were not in fact alone in their struggle against AIDS and they had for the first time lived in an environment where they were not stigmatized. The children also reported appreciating the good relationship with the facilitators and enjoyed the logistics and the environments where they did MWT.

4.5.5 The benefits of the group to children—Informal caregivers

Most of the informal caregivers were optimistic out their children benefiting from the group. The grandmothers each pinpoint some immediate changes they saw in both the new skills and the social interaction, which they felt, were rather new. Even though some showed some pessimism, they were general confidence that children brought something new in their families. It is interesting to note the grandmothers realized the resilience in the way their children approached their AIDS status as quoted in table 4-18 below.

Table 4-18 The benefits of the group to children--Informal Caregivers

ID No.	The benefits on the group to children—informal caregivers
C4	*"It's only about a week ago since the children completed this seminar; I believe I will have a lot to say after observing, I would like to see how the memory book is going to make my grandson become a better person".*
C8	*"Yes it was very helpful; those children have challenges living with HIV and AIDS, having them sit down and reflect about their lives as children with challenges, it opens a new page in their lives" This helps the children learn how to live and it is much easier for them to learn from new people".*
C11	*"Yes of course and the child has developed a lot of skills. She is very proud about the skill of making the memory box and book"*
C14	*"It is not too early to say if they group has been helpful or not but time will tell, I have however seen that my grandchild is able to talk about her HIV and AIDS status with easy.*
C17	*"You may realize that life is becoming too hard these days and it is quite rear for a child to have this opportunity; my grandson is able to talk about caring for the great memories of his parents through the memory box. This is amazing for me".*
C19	*"The seminar was very helpful to children in many ways. Of course, there could be some shortcoming such as transport allowance for the children. The children have a new vocabulary in the family—I am a hero!" 'The children learnt a lot of things such as discipline and my child was very happy with the food"*
C21	*"I do not think you need more time to know the difference those children had made, For example my granddaughter talks about her new friends and she is very proud about this".*
C25	*"Yes; my grandson is very happy with a new name and I would like to call him 'PEACE' even at home"*
C31	*"Yes, I am happy that she dedicated the memory book to me and I feel the child is much happier"*
C37	*"Yes indeed. It has been seen; he is happier and ever closer to me".*
C42	*"Yes. He has since been able to talk about his adherence to medication. I think he will be able to better deal with his health challenge"*
C47	*I have a lot of expectation and I feel there is something new from her; she is talking about being HIV and AIDS with much easy as mentioned by one of the caregivers"*

Source: Data base RCTII Memory work PASADA

There are some specific information, which the caregivers provided about the benefits of the group to the children and youths. The caregivers realized that this was a great opportunity as noted by participant ID no C8:

"Yes it was very helpful; those children have challenges living with HIV and AIDS, having them sit down and reflect about their lives as children with challenges, it opens a new page in their lives" This helps the children learn how to live and it is much easier for them to learn from new people".

The caregivers noted some change in the behavior of their children and youths. This is seen in participants ID no.C11, C21, C25, C31, C37, C42 and C47. For example, C47 shared that:

"I have a lot of expectation and I feel there is something new from her; she is talking about being HIV and AIDS with much easy as mentioned by one of the caregivers"

4.5.6 Preparation of the children to attend the seminar and how to improve the process

The informal caregivers generally found it very easy to allow the children to attend the therapy even though there were some indications of some difficulties. Some registered, it was not necessary to sign consent forms, since they are not literate and it would be better to base the consent on the long term relationship that exists with PASADA. Some acknowledged the importance of the formal system used for the recruitment of their children, but it would have been much better if the informal caregivers could participate in MWT as quoted in table 4-19 below:

Table 4-19 Preparation of the children to attend the group and how to improve the process

ID No.	*Preparation of the children for MWT*	*How to improve the process*
C4	*"Yes it was fine"*	*"I would however suggest that the informal caregivers should be invited and attend too"*
C8	*"It was fine and I was very happy"*	
C11	*"The process was very fine since it involved the school and the caregiver;*	
C14	*"A bit difficult since she is the only girl living with me and staying away for 5 days was very hard for me as an old woman. It is very good the way it was".*	*"Yes but it would be better for this seminar to include the informal caregivers at the same time. This would make it very easy for us to learn what the children are doing too"*
C19	*"Yes it was indeed very easy and the child was very happy with this".*	*"It is not necessary for you to invite us using a written consent form after all we have been working together for some time now?"*
C21	*"The whole process was fine"*	*But there would be need for more preparation with the whole family".*
C25	*"As mentioned by others the process was perfect and no need for any changes.*	
C31	*"There wasn't any problem with the process;*	
C37	*"Yes I agree with what the others have said especially the question of written invitation".*	*"But do you think it is necessary for the old people like me to sign. I can't even hold a pen?"*
C47	*"I did not believe that my granddaughter would be saying the truth unless the there was a written document. The arrangement was very fine"*	

Source: Data base RCTII Memory work PASADA

4.5.7 Suggestions to improve the children's group

The informal caregivers generally agreed the number of children participating should increase even though they did not indicate the exact number (C19,). There was however, one caregiver who expressed her spiritual discomfort related to her Islamic religion (C21). Some caregivers C4) insisted they should also attend the MWT, increasing the number of the participants and revision of how MWT could reduce stigma C4). The quotations in table 4-20 below provide some details:

Table 4-20 Suggestion to improve the children's group

ID No.	*Suggestions to improve the children's groups*
C4	*"When the informal caregivers go through those seminars, it would reduce stigma"*
C11	*"There would be need for children to repeat this exercise"*
C19	*"More children should be given this seminar"*
C21	*"It is very good but I would suggest the girls and boys could attend separately. It is not good for the girls and boys to mingle frequently, it is against Islam"*
C42	*"Informal caregivers should have the same seminar so that they could effectively support those children"*
C8	*"Those children who have already attend could attend again so that they could revise what they learnt"*

Source: Data base RCTII Memory work PASADA

5 CHAPTER FIVE

5.1 Discussion

5.1.1 Achievement of the aim and the objectives of the trial

- Despite the challenges faced by the researcher, the children and the informal caregivers who participated in the trial, it was very successful. We reached all the first three objectives and therefore it was possible to see the feasibility of an optimal trial in the fourth objective. One would ironically say that, *for the past 10-year of MWT provision without rigorous evaluation and documentation of MWT, PASADA had unknowingly been creating a solid environment for an ethical RCT Phase II on MWT as part of PSS in Palliative Care.* Indeed MWT has positive outcomes to fully orphaned children in terms of their self-esteem, coping and multidimensional wellbeing.

The findings of this trial provide the much-needed documentation in Palliative Care beyond HIV especially among children and adolescents. This trial provides the needed data in Palliative Care to ensure this approach in medicine could reach the ever-increasing number of children and adolescents who are living with HIV and AIDS. This is therefore in line with the UNAIDS and WHO recommendations for more healthcare support for adolescent in the fight against HIV and AIDS. With the law in Tanzania requiring people with HIV and AIDS be protected and have access to health care, the achievement of this trial will reflect the different efforts that non-governmental organizations are contributing in the implementation of this law. This should enhance law enforcement for Palliative Care as a right and a question of justice, especially to children and adolescents with life limiting and threatening illnesses. The Sub-Saharan region is the most affected region in the world with HIV and AIDS; these results should provide evidence for effective treatment and care for AIDS as a chronic illness among children and adolescents. This will entail ensuring patients have access to Palliative Care with PSS as one of the requirements in any holistic care approach. MWT as PSS in Palliative Care, we have the required treatment and care that will empower patients, especially children and adolescents with AIDS build resilience against the many challenges related to AIDS such as orphan-hood, adherence to medication and other stressful situations that prevent effective adolescence well-being. This would reduce the HIV infection rate as we move toward an HIV free society.

5.1.2 Strength of the study

- It was very easy to integrate this trial with the normal routine of the services of PASADA. Therefore, the organization did not have to make a special funding for this study. This made it very easy for the organization to give permission for the study to be done at PASADA.
- Since Palliative Care has been at PASADA since 2002, most the HCP understand the practice of Palliative Care. There was minimum expenditure on training for research assistants
- It was relatively very easy to find the participants for the trial since the randomization was integrated in the routine activities of PASADA.
- There was no need to calculate the sample since over the 8 years that MWT has been done in two different groups within an interval of 6 months, PASADA was creating a natural and ethical *'experimental and wait list groups'*.
- Repssi manuals are readily available at PASADA making it very easy to go straight into the trial
- The findings do not only implement the recommendations for more documentation or research beyond HIV in Palliative Care in Africa, but also gave chance for PASADA to demonstrate that it is really one of the beacon centers of Palliative Care in Africa.
- The study provides information on the efforts that Palliative Care is doing in the fight against HIV and AIDS especially among the children adolescents.
- This study in one way or another evaluated Repssi efforts in mainstreaming PSS in healthcare especially, among children and the results are positive at least from PASADA's point of view.

5.1.3 Weaknesses of the study

- Since we had to compare two groups that mixed girls and boys, mixing the sexes went against some religious norms of some children and their informal caregivers. It is therefore very important to see how this could affect their spirituality in some cases.

- It is relatively a very expensive trial and this would challenge how the phase III trial would be implemented on a larger scale.

5.1.4 Challenges faced

- Like most of the FBO, PASADA is entirely donor dependent and it will always remain difficult to find donors. Had it not been the reallocation of some funds from other programs to MWT, this trial would not have taken place as planned. As old as Palliative Care is, this healthcare

service remains strange to many HCP and Executive Directors. When MWT was to be integrated into this trial in 2013, PASADA was asked by donors to do away with some activities in order to meet budget requirements. Unfortunately, MWT was one of the activities listed for laying-off. Therefore, the budget for MWT was deleted and we had to depend on reallocated funds from other activities.

- It was not easy to get ethical clearance from NIMR Tanzania. It was so difficult to follow up since we had to go to their offices many times before official ethical clearance was granted.

5.2 Recommendation

5.2.1 **Memory Work therapy**: This therapy as part of PSS should be promoted as one of the most effective non-pharmacological interventions that could capture the role of the family in Palliative Care.

5.2.2 **Number of participants**: the number of children who should participate in a given group therapy should adhere to the ethical requirement of group therapy. It is however very important to ensure more children and their families have access to MWT without compromising the quality of life of each family (intention to treatment and care) and ensure HCP burnout management is in place.

5.2.3 **Participation of the informal caregivers**: While Repssi recommends informal caregivers participate in MWT activities; this entails high costs especially in group therapy process that has many interrelated activities. It is therefore important for stakeholders to see how this could be integrated even at very low costs for this is one of the characteristics of Paediatric Palliative Care

5.2.4 **Informed consent**: While most of the informed consent processes require someone to be literate, it would be very important to device alternatives that would capture individuals who are illiterate but who are very important contributors in Paediatric Palliative Care Transport allowance: this is a very demanding area of logistics in organizing boarding therapies especially in developing countries. The transport infrastructure is very poor and low-income patients are many. It should therefore be done carefully to ensure that each participant is comfortable.

5.2.5 **Mixing girls and boys in MWT**: The question of when should the girls and boys mix during group therapy is crucial especially, in Paediatric Palliative Care. Care should be taken to ensure that this does not go against the patient's way of life especially from the spiritual and religious point of view for they both play an important role in care and treatment in Palliative Care

5.2.6 **Memory book and box**: while those two exercises are one of the most interesting to children, the challenge is that they would need places to keep them. In resource poor countries where most of the families have economically become very poor, many families do not have proper houses where to store those items. Customized activities that would have similar effects should be promoted

5.2.7 **Palliative Care and MWT**: Since the children and informal caregivers find MWT very instrumental in care and treatment, more efforts are required to mainstream MWT method in Palliative Care

5.2.8 **PASADA**: PASADA as one of the beacon centers of Palliative Care in Africa has the duty to promote MWT in Palliative Care. Deliberate efforts should be made to integrate MWT in all its healthcare interventions so that all the children receive MWT and ensure its sustainability

5.2.9 **MoHSW**: the ministry should support any efforts to mainstream MWT in healthcare at all levels

5.2.10 **UCT Researchers**: there is a need for evidence-based information on how MWT could best be implemented in Paediatric Palliative Care for the ever-increasing number of children who have life threatening and limiting illnesses in low-income countries.

5.3 Conclusion

The aim of the trial in which we had to check whether MWT has a positive outcome for fully orphaned children who are on ART was achieved.

To measure psychosocial well being of orphans on HIV and AIDS treatment before attending the MWT: this objective was reached since the experimental and the wait list groups were comparable. This means the randomization was very successful. There were however some differences in the CD4 count and BSI total score at baseline between the two groups and would adjust for that.

To investigate the use of coping skills learnt in MWT seminars at PASADA: this objective was reached since the participants become very conversant with MWT coping skills and this was during MWT and the FGD. The children learnt how to make memory books and boxes. Using those items they able to establish their important memories and discover their heros in their famillies and how themselves were hero in builiding resilience in livng with AIDS. With the tree of life and the different windows in their life, they were able to realise their relationship to different people in their lives and how they helped in climbing their ladder of of ambitions

To evaluate the groups in terms of outcome compared to existing standard care (without MWT): this objective was reached in that there was a difference between the experimental and the wait list groups. At (Time 0) T0, both groups went through the first phase of questionnaires and both groups were basically the same with P value less than 95% indicating the significant similiarities of the participants at T0 before the experimental group received MWT. For example P value of age was P=0.695. At T1 both groups again went through the same questionnaires for the second phase. The results showed that there was a change in the B value when moving from the experimental to the wait list groups. There was a better outcome in the experimental group than the wait list group. There was further improvement in the experimental group at T2. The B Value for BSI at T1was B=44.985 and at T2, it rose to 46.668. There was a similar trend in the results of the other measuring tools. The RSES changed from B=-1.922 at T1 - B=-4.392 at T2, SDQ Goodman 1997 total difference of B=4.803 at T1 - B=5.218 at T2. The SEQC's two scales had the similar changes: the social scale B=-4.539 at T1 - B=-7.791 and the emotional scale changed from B=-5.803 at T1 - B=-9.007 at T2.

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7 Appendices

A. Focus Group Discussion Children English/Swahili

Focus Group: children

Can you tell me what you remember about the group, what did you do there?

What did you enjoy? Why?

If we did it differently what should we change?

Has the group helped you in any way, what why?

Was there anything that was unhelpful?

Who do you think the group would be good for?

Was it the right length, was a week good? And was it the right number of children?

What else would you like to say about the group?

Swahili Translation

Kikundi Taswira (Watoto)

Je unaweza kuniambia nini unekumbuka katika semina ya kumbukumbu ya maisha, na ulinfanya nini kwenye semina?

Je nini kilikufurahisha na kwa sababu gani?

Je ikiwa tulifanya tofuati, nini kibadilishwe/kuboreshwe?

Je semina ya kumbukumbu ya maisha imekusaidia kwa njia yoyote fulani, imekusadia nini na kwanini

Je kulikuwa nakitu chochoe ambucho hakikuwa na manufaa?

Je unafikiri semina hii inafaa kwa nani, Kwa nani?

Je muda ulitosha, wiki moja inatosha, idadi ya watoto ilikuwa sahihi?

Je unamaoni mengineyo kuhusu semina?

B. Focus Group Discussion Informal caregivers English/Swahili

Focus Group: caregivers

How did you feel about the child attending the group? Did you have any concerns?

Did the child talk to you about the group and what happened? What did they tell you?

Did they tell you if they enjoyed it, if so what did they like?

Do you feel it helped the child, if so why?

Do you think it was unhelpful in any way?

Was it easy to arrange for the child to attend; is there anything we could do to make it easier to attend?

What do you think a group could offer children that would be helpful?

Swahili translation

Kikundi Taswira (Walezi)

Je unahisi nini kuhusu watoto kuhudhuria semina ya kumbukumbu ya maisha? Je ulikuwa na mashaka yoyote?

Je watoto walizungumuza chochote kuhusu semina na aliyotokea? Walizungumzia nini?

Je watoto waliwambia wamefurahia kushiriki? Ikiwa ndivyo walifurahia nini?

Je unafikiri zowezi la kumbukumbu ya maisha inawasaidia watoto? Ikiwa ndivyo kwa nani?

Je unafikiri semina haikuwa lamuhimu kwa njia yoyote?

Je ilikuwa rahisi kumuandaa mtoto kushiriki katika semina ya Kumbukumbu ya maisha? Je unamapendekezo yoyote kukurahisishia kuandaa mtoto ashiriki?

Je unamapendekezo yoyote kwa ajiri ya kuboresha huduma ya kumbukumbu ya maisha

C. Children's Consent Form Swahili version

Idhini ya kushiri

Tamko la kushiriki (MTOTO)

Nathibitisha kwamba nimesoma na kuelewa fomu na taarifa tarehe .... / .../20 ... kwa ajili ya zoezi hapo juu na nilikuwa na nafasi ya kuuliza maswali.

Naelewa kwamba kama nikiamua wakati wowote wa zoezi kujiondowa mara moja, nitawazisiana na mratibu husika kumueleza niondolewa na katika hilo huduma yangu ya matibabu au haki za kisheria hazitaathirika.

Mimi nakubaliana nautumiaji wa taarifa zangu binafsi na zamatibabu kwa madhumuni ya utafiti huu. Mimi naelewa kwamba taarifa hizo zitatashughulikiwa kwa siri kubwa.

Ninakubali kushiriki katika utafiti hapo juu.

_____ (Jina)

Saini

Mtoto au _____ | *Kidole gumba:* | *Tarehe* _____

Mlezi au _____ | *Kidole gumba:* | *Tarehe* _____

Tamko la mtoa huduma ya afya:

Mimi_____ (Jina)

Nathibitisha kwamba nimeelezea kwa umakini hali na matakwa ya utafiti kwa mlezi.

Saini Tarehe

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D. Consent form for informal caregivers Swahili version

Idhini ya kushiri

Tamko la kushiriki (Walezi)

Nathibitisha kwamba nimesoma na kuelewa fomu na taarifa tarehe .... / .../20 ... kwa ajili ya zoezi hapo juu na nilikuwa na nafasi ya kuuliza maswali.

Naelewa kwamba kama nikiamua wakati wowote wa zoezi kujiondowa au mtoto wangu mara moja, nitawazisiana na mratibu husika kumueleza niondolewa na katika hilo huduma yangu ya matibabu au haki za kisheria hazitaathirika.

Mimi nakubaliana nautumiaji wa taarifa za mtoto wangu binafsi na zamatibabu kwa madhumuni ya utafiti huu. Mimi naelewa kwamba taarifa hizo zitatashughulikiwa kwa siri kubwa.

Ninakubali kushiriki katika utafiti hapo juu.

_____ (Jina)

Saini: _____ au *Kidole gumba* Tarehe _____

Jina la mtoto ninae ruhusu kushiriki katika utafiti

_____(Jina)

Tamko la mtoa huduma ya afya:

Mimi_____ (Jina)

Nathibitisha kwamba nimeelezea kwa umakini hali na matakwa ya utafiti kwa mlezi.

Saini Tarehe

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E. Assent form for children (English/Swahili)

ASSENT FORM FOR CHILDREN[10]

Explain the following to the child in a language s/he can understand when s/he has assented to talk in presence of the a legal caregiver:
Swahili: ***Muelezee mtoto kifuatacho katika lugha nyepezi akikubali kuongea mbele ya mlezi wake halali:***

- **What is the aim of the study:** To determine whether Memory Work Therapy improves outcomes for you who is an orphan and on antiretroviral therapy, in terms of your self-esteem, coping and multidimensional wellbeing
  Lengo la utafiti huu: *Kuamua kama Tiba ya Kumbukumbo inaboresha matukio kwako wewe yatima ambaye uko katika tiba yakupunguza makali ya Ukimwi, katika suala la heshima yako binafsi, kukabiliana na ustawi wako katika nyanja mbalimbali*

- **Who is doing the study**? This study is being done by Elvis Joseph Miti—a Palliative Care Paediatrician and Social Worker on behalf of PASADA which takes care of people with illnesses like yours.
  Mtafiiti ni nani? *Mtafiti ni Elvis Joseph Miti-mudumu wa Tiba Shufaa kwa watoto, afisa Ustawi wa Jamii kwa niaba ya PASADA ambayo inatoa huduma ya watu wenye magonjwa kama yako.*

  Why are we doing this study? We are doing this study so that we can find how memory work therapy improves your self-esteem and overall coping wellbeing before we could effectively extend this therapy to your peers at PASADA and other health care facilities
  Kwa nini tunafanya utafiti huu? *Tukufanya utafiti huu ili tuweze kujuwa jinsi tiba ya kumbukumbu inaboresha kujiami kwako yako binafsi na kwa ujumla kukabiliana ustawi wako kabla hatuja eneza kwa ufanisi tiba hii kwa wenzako katika PASADA na vituo vya afya vingine*

- **What will happen during the study?** I will on three occasions ask you a few questions about your self-esteem and different coping wellbeing. You will also participate in 5 day residential memory work therapy at a beautiful venue that will be communicated to you before taking part in FGD with your peers. Your caregiver will also take part in FGD
- **Ni nini kitatokea wakati wa utafiti**? *Katika awamu tatu, nitakuuliza maswali machache kuhusu kujiami kwako binafsi na mbinu mbalimbali za kukabiliana na ustawi wako. Pia utashiriki katika semina ya siku 5 ya Tiba kumbukumbu katika ukumbi nzuri kama utakavyataarifiwa na kabla ya kuchukua katika Kundi Mazungmuzo wenzako. Mlezi wako pia atashiriki katika Kundi Mazungmuzo.*

- **Are there good things and bad things about the study?** The good thing about the study is that you will participate in 5 day residential memory work therapy and you will learn different skills of coping with your orphan-hood and ART treatment. You might, however, find some of the questions and exercise difficult.
  Je, kuna mambo mazuri na mabaya katika utafiti? *Jambo zuri kuhusu utafiti ni kwamba utashiriki katika semina ya Tiba Kumbukumbu ya siku 5 na utajifunza mbinu mbalimbali ya kukabiliana na hali ya uyatima- na matibabu ya kupunza makali ya UKIMWI. Utaweza, hata hivyo, kupata baadhi ya maswali na mazowezi kuwa magumu.*

- **Who will know about what I did in the study?** No one will know apart from your parent/ legal guardian and the few people doing the study; no else will know that you are involved.
  Nani atujua ushiriki wangu katika utafiti? *Hakuna mtu atakejua isipokuwa mzazi wako / mlezi wa halali na watu wachache watakaoshiriki katika utafiti, hakuna mwingine watajua kwamba unashiriki.*

- **Can I decide if I want to be in the study?** You can decide to be in the study or not. Nobody will be angry or upset if you do not want to be in the study. We are also talking to your parent / legal guardians about the study as they have to say that it is OK for you to be involved and we will have to ask them some questions as well. If the parent /legal guardian agrees that it is Ok for you to get involved, you can decide to talk to me in the presence of your parent/legal guardian or alone.
  Je, nawezakuamua kushiriki katika utafiti? *Unaweza kuamua kushiriki katika utafiti au la. Hakuna atakaye athirika usiposhiriki katika utafiti. tunazungumza na mzazi wako / walezi halali kuhusu utafiti kama ni sawa kwa wewe kushiriki na tutakuwa na tutawauliza baadhi ya maswali pia. Kama mzazi / mlezi wa halali anakubaliana ni sawa kwa wewe kushiriki, unaweza kuamua kuzungumza na mimi mbele ya mzazi wako / mlezi wa halali au peke yake.*

  Agreement to participate in the study/ *Kukubali kushiriki katika Utafiti*
  ID number and Signature of the Child……..Date……Signature of the caregiver…….Date…….

NB: This assent form will be used for verbal children aged 14 years to 18 years.

[10] The template is adapted from the assent template from the Hospital for Sick Children in Toronto, Canada.

F. Consent form for children English version

Participant's Statement: Child

I confirm that I have read and understand the information sheet dated …./.../20… for the above activity and have had the opportunity to ask questions.

I understand that if I decide at any other time during the activity that I no longer wish to participate in this project, I can notify the coordinator involved and be withdrawn from it immediately without my medical care or legal rights being affected.

I consent to the processing of my personal and medical information for the purposes of this research study. I understand that such information will be treated as strictly confidential.

I agree to take part in the above study.

_____ (name)

child

Sign _____ **or** Fingerprint **Date** _____

Informal caregiver

Sign _____ **or** Fingerprint **Date** _____

Healthcare worker's statement:

I_____ (name)

Confirm that I have carefully explained the nature and demands of the proposed research to the carer.

Signed **Date**

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G. Consent form for informal caregivers English version

Participant's Statement: Caregiver

I confirm that I have read and understand the information sheet dated …./.../20… for the above study and have had the opportunity to ask questions.

I understand that if I decide at any other time during the research that I no longer wish myself or my child to participate in this project, I can notify the researchers involved and be withdrawn from it immediately without my child's medical care or legal rights being affected.

I consent to the processing the personal and medical information of my child and I for the purposes of this research study. I understand that such information will be treated as strictly confidential.

I agree to take part in the above study.

_____ (name)

Signature

Caregiver _____ or Fingerprint Date _____

Name of child for whom consenting to participate in the study:

_____ (name)

Healthcare worker's statement:

I_____ (name)

Confirm that I have carefully explained the nature and demands of the proposed research to the carer.

Signed **Date**

H. Tools and measures

Identification number [ID No.]…… Date of interview:…….

TAARIFA BINAFSI/DEMOGRAPHIC INFORMATION (Swahili/English)

The 'Swahili' questions are in second person to facilitate *researcher administrated* questionnaire process

<table>
<tr><td colspan="3">OVC:</td><td colspan="7">Kiwango cha elimu/Eduction Level</td><td colspan="3">Makazi</td></tr>
<tr><td colspan="3">Jensi/sex</td><td colspan="7">Shule ya msingi/ Primary school</td><td>Wilaya/District</td><td>Kata/Ward</td><td>Mtaa/Street</td></tr>
<tr><td>Me / M</td><td>Ke/ F</td><td>Nyigine/ Others</td><td>1</td><td>2</td><td>3</td><td>4</td><td>5</td><td>6</td><td>7</td><td>Kinondoni</td><td></td><td></td></tr>
<tr><td colspan="3">Umri/ Age</td><td colspan="7">Shule ya sekondari/ Primary school</td><td>Temeke</td><td></td><td></td></tr>
<tr><td>14</td><td>15</td><td>16</td><td>I</td><td>II</td><td>III</td><td>IV</td><td>V</td><td>VI</td><td></td><td>Ilala</td><td></td><td></td></tr>
<tr><td>17</td><td>18</td><td></td><td colspan="7">Ufundi/ vocational training</td><td>Chalinze</td><td></td><td></td></tr>
<tr><td></td><td></td><td></td><td colspan="7" rowspan="2">Hayupo shuleni/ not at school</td><td>Mkuranga</td><td></td><td></td></tr>
<tr><td colspan="3"></td><td>Rufiji</td><td></td><td></td></tr>
<tr><td colspan="12">Taarifa za kaya/household information</td></tr>
<tr><td colspan="3" rowspan="2">Baba alifariki mwaka gani: Father died in</td><td colspan="3" rowspan="4">Muko watu wangapi katika kaya yenu?/ How many individuals are living your house?</td><td colspan="3" rowspan="4">Nani anakulea? Who is caring for you?</td><td>Bibi/ Grandmother</td><td>Babu/ Grandfather</td><td>Shangazi/ aunt</td></tr>
<tr><td colspan="2">Mjomba/ Uncle</td><td colspan="2">Watoto wanaojilea Child headed family</td></tr>
<tr><td colspan="3">Mama alifariki mwaka gani: Mother died in:</td><td colspan="4">Wengine Taja/ others, mention</td></tr>
<tr><td colspan="3">Sina uhakika Not sure</td><td colspan="4" rowspan="2"></td></tr>
<tr><td colspan="3">Sijui: I do not know:</td></tr>
<tr><td colspan="4">Elimu ya mlezi Education of the caregiver</td><td>Msingi Primary</td><td>Sekondari Secondary</td><td>Ufundi/ Elimu ya juu Vocational training/ higher learning</td><td>Sijui/ I do not know</td><td>Hana/ none</td></tr>
<tr><td colspan="4">Kitega uchumi/ Income activity</td><td>Mkulima/ Peasant</td><td>Kaajiriwa/ Employed</td><td>Biashara /ndogodogo Micro business</td><td>Sijui/ I do not know</td><td>Hana/none</td></tr>
<tr><td colspan="12">CD4 count……. Latest viral load……..
NB: Check from the CTC card</td></tr>
</table>

Identification number [ID No.]…… Date of interview:…….

Brief Symptom Inventory (BSI)

Ivi punde nitakusomea orodha ya matatizi na manunguniko ambayo watu huwanayo. Kwa kila moja niambia kwa kiwango gani linakusumbua au kukusononesha katika kipendi cha wiki iliyo pita hadi leo. Tafadhali niambie ikiwa kila tatizo hilo halikusumbua kabisa, angalau, kiasi, kweli kabisa. Au hutaki kujibu kabisa

I am going to read a list of problems and complaints that people sometimes have. For each one, tell me how much that problem has bothered or distressed you during the past week, including today. Please tell me whether each problem has bothered you not at all, a little bit, moderately, quite a bit, or extremely(Leonard R. Derogatis, 1993)**. You may refuse to answer the question**

	halinisumbui kabbisa / Not at all	***angalau*** / A little bit/	***kiasi*** Moder-ately	***naelekea*** Quite a bit/i	***kweki kabisa*** Extremely/	***sijibu*** //Refuse to Answer/
	0	1	2	3	4	**8**
Unajisikia kama uwaga au unatetemeka ndani Nervousness or shakiness inside						
Unaskia mchoko (lepe) or kuishiwa nguvu(kizunguzungu) Faintness or dizziness.						
Unajisikia kama vile mtu mwingine anaweza kudhibiti mawazo yako The idea that someone else can control your thoughts.						
Unahisi watu wangine ni visababishi vya matatizo yako Feeling others are to blame for most of your troubles.						
Unamatatizo kukumbuka matukio au vitu (mambo) Trouble remembering things.						
Unakasilika upesi Feeling easily annoyed or irritated.						
Maumivu moyoni au kifuani Pains in heart or chest.						
Unahisi hofu ya maeneo wazi Feeling afraid in open spaces.						
Unamawazo ya kujiuwa Thoughts of ending your life.						
Unahisi kana watu wengi hawaaminiki Feeling that most people cannot be trusted.						
Unahisi hamu yakula mdogo Poor appetite.						
Unaskia hofu ghafla bila sababu ya msingi Suddenly scared for no reason.						
Huwa na hasila ghafla ambayo huwezi kudhibiti Temper outbursts that you could not control.						
Unahisi kujisikia mpweke hata ukiwa na watu Feeling lonely even when you are with people.						
Unahisi kuzuuliwa kufanya vitu Feeling blocked in getting things done.						
Unahisi upweke Feeling lonely.						
Unahisi kujisikia ovyo						

Feeling blue.						
Unahisi hupendelei chochote Feeling no interest in things.						
Unahisi uwog/kutishiwa Feeling fearful.						
Unahisi kuumizwa upesi Your feelings being easily hurt.						
Unahisi watu hawana urafiki au hawakupendi Feeling that people are unfriendly or dislike you.						
Unahisi wachini/duni kuliko wengine Feeling inferior to others.						
Unahisi kutapika au shida ya tumbo Nausea or upset stomach.						
Unahisi kuchunguliwa au kusengenya Feeling that you are watched or talked about by others.						
Una hisi tatizo kupata usingizi Trouble falling asleep.						
Unatabia yakurudia kwa kukithiri ulicho fanya tayari Having to check and double check what you do.						
Unahisi nimzito katika kuchukuwa maamuzi Difficulty in making decisions.						
Unahisi uwoga kusafiri kwa basi, barabara hadhini, au garimoshi Feeling afraid to travel on buses, subways, or trains.						
Unahisi tatizo la kuhema Trouble getting your breath.						
Unahisi joto or baridi Hot or cold-spells						
Unahisi uwoga wakushriki katika matukio, maeneo, shughuli kwa sababu yanakutisha Having to avoid certain things, places, or activities because they frighten you.						
Unahisi kama huelewi kinachoendelea Your mind going blank.						
Unahisi ganzi katika baadhi ya sehemu ya muili wako Numbness or tingling in parts of your body.						
Unahisi kustahili kuadhibiwa kwa dhambi zako The idea that you should be punished for your sins.						
Unahisi kukata tamaa Feeling hopeless about the future.						
Unahisi matatizo kutulia Trouble concentrating.						
Unahisi mzaifu katika sehemu za muili wako Feeling weak in parts of your body.						
Unahisi kusakamwa au kufungiwa Feeling tense or keyed up.						
Unawaza ju ya kifo na kufa Thoughts of death or dying.						
Unakuwa na msukuma wa kupiga, kujeruhi, au kuumiza mtu Having urges to beat, injure, or harm someone.						
Unakuwa na msukumo wa kubomoa or kuvunja vitu Having urges to break or smash things.						

Unahisi kujihami sana ukiwa na watu wangine Feeling very self-conscious with others.						
Unahisi vibaya ukiwa katikati ya umati Feeling uneasy in crowds.						
Unahisi hujawahi kuwa karibu na mtu au rafifki wa karibu Never feeling close to another person.						
Unahisi matukio ya kuwogofya au taharuki Spells of terror or panic.						
Unahisi kuwa katika ugomvi mara kwa mara Getting into frequent arguments.						
Unahisi uwoga ukiachwa peke yako Feeling nervous when you are left alone.						
Unahisi watu hawakupongezi kulingana na uwezo wako Others not giving you proper credit for your achievements.						
Unahisi huna utulivu sana na huwezi kuka sehemu mmoja Feeling so restless you could not sit still.						
Unahisi kutokuwa na thamani au hadhi Feelings of worthlessness.						
Unahisi watu watakutumia vibaya ukiwaachia Feeling that people will take advantage of you if you let them.						
Unahisi umekosea au una hatia Feelings of guilt.						
Unawaza kunakasoro kitwani mwako The idea that something is wrong with your mind.						

Identification number [ID No.]…… Date of interview:…….

Strength and difficulties (SDQ)

Kwa kila kipengele nakuomba ujibu Siyo kweli, kweli kiasi au Hakika Kweli. Itakusaidia endapo utjibu vipengele vyote vizuri kadiri uwezeavya hata kama huna uhakika au vipngele havionehsi kuwa na naan kwako. Tafadhali jibu kwa kuzingatia hali yako katika kipindi cha miezi sita iliopita

I would like you and me to go through the different aspect of a child's life you. Depend how you related to those different aspects of yourself, you are free to disagree (**not true**) or answer '**somewhat true**' and you could are **'Definitely true'**. Pease try to provide you view for each area even when you thing you are not so sure. You respond according to your past six month life experience(Robert Goodman, 2005)

	Siyo kweli/ **Not true!**	***Kweli kiasi/*** **Somewhat true!**	***Hakika kweli/*** **Definitely true!**
Una jaribu kuwa mwema kwa watu wengine. Unajali hisia zao I try to be nice to other people. I care about their feelings			
Huwezi kutulia, huwezi kutulia sehemu moja kwa muda mlefu I am restless, I cannot stay still for long			
Una pata maumivu ya kichwa, tumbo au homa mara kwa mara I get a lot of headaches, stomach-aches or sickness			
Ni kawaida kwako kushirikiana/kugawana/kutoa kwa/ na wengine (chakula, micheso, karamu na kadhalika) I usually share with others (food, games, pens etc.)			
Ni wepesi wa hasira na mara kwa mara kushindwa kujizuia I get very angry and often lose my temper			
Mara kwa mara nimpweke. Hucheza peke yangu . I am usually on my own. I generally play alone or keep to myself			
Kwa kawaida hufanya ulichoambiwa I usually do as I am told			
Huwa unawasiwasi sana I worry a lot			
Ni wepesi wa kusaidia aliyeumia, aliyekasilika au mwenye ugonjwa I am helpful if someone is hurt, upset or feeling ill			
Mara kwa mare hutulii mahali sehemu moja I am constantly fidgeting or squirming			
Una rafiki mwema au zaidi I have one good friend or more			
Nimu kakamavu na unauwezo wa kuwafanya watu kukutimizia utakacho I fight a lot. I can make other people do what I want			
Mara kwa mara huna furaha, machozi kukutoka (kulia) wepesi I am often unhappy, down-hearted or tearful			
Watu wa umri wako kwa ujumla wanakupenda Other people my age generally like me			
Ni mwepesi kuvulugiwa mawazo. Ni vigumu kutulia/kiwa makini I am easily distracted, I find it difficult to concentrate			
Ni hofu ya matukio/jumbo/mazingira mapya. Ni mwepesi wakupoteza kujiamini I am nervous in new situations. I easily lose confidence			
Ni mukarimu/mwema kwa watoto wadogo I am kind to younger children			

Mara kwa mara unasingiziwa/ analaumiwa umedanganya au muongo I am often accused of lying or cheating			
Watoto wenzako au vijana hufanya ubabe/ kukuchokoza/kukuonea Other children or young people pick on me or bully me			
Mara kwa mara kujitolea kusaidia wengine kama vile walezi, walimu na watoto I often volunteer to help others (parents, teachers, children)			
Una fikiri kabla ya kutenda I think before I do things			
Una tabia ya udokozi nyumbani, shuleni na maeneo mengine I take things that are not mine from home, school or elsewhere			
Ni rahisi kwako kushirikiana na watu wazima kuliko watu wa rika yako I get on better with adults than with people my own age			
Unahofu nyingi na ni mwepesi wakuogopa I have many fears, I am easily scared			
Umemaliza kazi uliyoanza. Umakini wangu ni mzuri I finish the work I'm doing. My attention is good			

Identification number [ID No.]…… Date of interview:…….

SELF-EFFICACY

Tunge penda utwambie jinsi unayo weza kufanya vitu kwa uzuri vilivyomo katika maswali yafuatayo

We would really want you to tell us about how well you can do the things in the questions below(Mueller et al., 2011)

	Not at all (hata)				**Very well (vema sana)**
					
	1	2	3	4	5
Ni kwa kiasi gani unaweza kutoa maoni yako wakati wanafunzi wengine hawakubaliani na wewe? How well can you express your opinions when other class-mates disagree with you?					
Ni kwa kiasi gani unaweza kujifurahisha mwenyewe wakati tukio baya imetokea? How well can you cheer yourself up when an unpleasant event has happened?					
Ni kwa kiasi gani kufanikiwa katika kuwa shwari tena baada ya tukio yakukuigifya sana? How well do you succeed in becoming calm again when you are very scared?					
Ni kwa kiasi gani unaweza kuwa rafiki na watoto wenzio? How well can you become friends with other children?					
Ni kwa kiasi gani unaweza kuzungumaza na mtu usiyemjua? How well can you have a chat with an unfamiliar person?					
Ni kwa kiasi gani unaweza kuzuia kuhamaki? How well can you prevent to become nervous?					
Ni kwa kiasi gani unaweza kufanya kazi kwapamoja na wanafunzi wenzio shuleni? How well can you work in harmony with your classmates?					
Ni kwa kiasi gani unaweza kudhibi hisia zako? How well can you control your feelings?					
Ni kwa kiasi gani unaweza kuwambia watoto wengi kwa ufurahii wanachokitenda? How well can you tell other children that they are doing some-thing that you don't like?					
Ni kwa kiasi gani unaweza kujifaliji ukihisi vibaya? How well can you give yourself a pep-talk when you feel low?					
Ni kwa kiasi gani unaweza kusimulia kichekesho kwa kundi la cha watoto? How well can you tell a funny event to a group of children?					
Ni kwa kiasi unaweza kuimarisha urafiki na watoto wenzio? How well do you succeed in staying friends with other chil-dren?					
Ni kwa kiasi unaweza kudhibiti mawazo mabaya? How well do you succeed in suppressing unpleasant thoughts?					
Ni kwa kiasi gani huna hofu ju ya tukio liwezekanalo? How well do you succeed in not worrying about things that might happen?					

Identification number [ID No.]…… Date of interview:…….

Self Esteem

Ifuatayo ni orodha ya vitu vinavyo husiana na hisia zako. Tafadhali nitakusaidia kuweka alama ya vema ili uonyeshi jinsi unavyo jisikia

Here is a list of things to do with your feelings. Please put a mark under how much you agree with what the statement says (Mueller et al., 2011)

	Agree a lot	agree	Disagree
Kwa ujumla, umeridhika na ulivyo On the whole, I am satisfied with myself			
****Siku zingine, unajisikia si mzuri vila*** At time, I think I am no good at all			
Una hisi una thamani kwa kiwango furani I feel that I have a number of good qualities			
Una uwezo wakufanya vitu kwa uzuri kama wanavyo weza watu wengine wengi I am able to do things as well as most of other people			
****Una hisi huna cha kujivunia*** I feel I do not have much to be proud of			
****Kwa kweli una hisi huna umuhimi nyakati furani*** I certainly feel useless at time			
Una hisi una umuhimu, angalao katika hali ya usawa na wengine I feel that I am a person of worth, at least on an equal plane with others			
Ugetamami ugejieshimu mwenyewe zaidi I wish I could have more respect for myself			
Kwa ujumla naegemelea kuhisi mimi ni mshindwa All in all, I am inclined to feel that I am a failure			
Una mtazamo chanya kwako mwenyewa I take a positive attitude towards myself			

Natumai umefurahia mahujiano yetu.
Asanta sana
Hope you enjoyed this interview
Thank you so much

I. PASADA clearance

PASADA
(Pastoral Activities and Services for People th AIDS Dar es salaam Archdiocese)

P.O. Box 70225
Dar es salaam—Tanzania
Phone: +255-22-2865451
Fax: +255-22-2866618
E-mail: pasada@pasada.or.tz
Website: www.pasada.or.tz

Services provided:
Voluntary Counseling & Testing
Home-Based & Palliative Care
Medical Assistance
Anteretro-viral Therapy
Prevention of Mother to Child Transmission
Support to Orphans & Vulnerable Children
Psychosocial Support
Community Education
Training

TUSAIDIANE PASADA

UNIVERSITY OF CAPE TOWN
School of Public Health and Family Medicine
Division of Family Medicine
Anzio Road
Observatory 7925
SOUTH AFRICA

4 June 2012

REF: AUTHORIZATION OF MR. ELVIS JOSEPH MITI, A SENIOR SOCIAL WORKER AT PASADA TO DO RESEARCH WITH CHILDREN AND THEIR CAREGIVERS AT PASADA ON MEMORY WORK THERAPY

Dear Sir/Madame:

With reference to the above heading, the named candidate is PASADA employee working, in the Orphans and Vulnerable Children's Department as a Senior Social Worker for the past five years. We recognize his efforts to contribute to our organization's objective to provide Holistic Care to our clients/patients especially children who are living with HIV and AIDS.

His research titled "**An evaluation of a psychosocial intervention for orphans on HIV Treatment: a Phase II RCT of Memory Work Therapy at PASADA, Tanzania**" is not only a privilege for the subject to build his capacity in Palliative Medicine but also in line with the organization's effort to evaluating the different services that we provided to our clients/patients.

Pastoral Activities and Services for AIDS Dar-Es-Salaam Archdiocese (PASADA) is therefore glad to authorize Elvis Joseph Miti to do this study in our organization for he has the skills and willingness to take up this challenge.

PASTORAL ACTIVITIES & SERVICES FOR PEOPLE WITH AIDS ★ DSM ARCHDIOCESE ★ PASADA P.O. BOX 70225 DAR ES SALAAM

Thank you
Signature removed
Jovin Tesha
Acting Executive Director -PASADA

J. REPSSI Clearance

REPSSI
Psychosocial Wellbeing For All Children

REPSSI Secretariat
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372 Oak Avenue
Ferndale, Randburg, South Africa

Phone: + 27 11 998 5820
Fax: + 27 11 789 6525
Email: info@repssi.org
Website: http://www.repssi.org

02 March 2012

Elvis Joseph Miti PPM, BAPhil, ADSW
Senior Social Worker (General)
OVC Department
PASADA
Email: mitiosjim@yahoo.com
Mobile: +255713434793

Re: Permission to use REPSSI materials for a Masters Dissertation

Dear Mr. Elvis Miti,

We trust you are well and thank you for choosing REPSSI materials to be your reference for your studies. Reference is drawn to your request to use REPSSI materials for a Masters Dissertation, on the research topic "Outcome of Psychosocial Support (PSS) for full orphaned children on ART; Randomized control trail (Phase II) investigation of the usage of coping skills for the most vulnerable children who undergo grieving and Memory Work sessions at PASADA".

REPSSI grants permission on the use of our materials with the following conditions:

- Acknowledging that the materials and content thereof are the property of REPSSI and cannot be used for any other purpose than that outlined in the scope of this letter. No part of REPSSI content may in any form or by any means (including through publication on any website) be reproduced, summarized, republished, adapted, copied, shared, or used in other training without the prior written consent of REPSSI.
- Any lessons learnt and findings from the study will be shared with REPSSI.
- Sharing an electronic copy of the final dissertation with REPSSI.

We trust you will find the above in order. We wish you all the best in your studies. Kindly contact us for any clarification.

Sincerely,

Signature removed

Noreen M Huni - Executive Director

Cc Miss UniWelva - Director of Social Enterprise, Finance and Administration
Cc Peter Masseso – East Sub Region Director

K. UCT Ethical Clearance

UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Faculty of Health Sciences Human Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

24 October 2012

HREC REF: 284/2012

Mr E Miti
c/o Prof R Harding
School of Public Health & Family Medicine
FHS

Dear Mr Miti

PROJECT TITLE: AN EVALUATION OF A PSYCHOSOCIAL INTERVENTION FOR ORPHANS ON HIV TREATMENT: A PHASE II RCT OF MEMORY WORK THERAPY AT PASADA, TANZANIA

Thank you for addressing the issues raised by the Human Research Ethics Committee.

It is a pleasure to inform you that the Ethics Committee has **formally approved** the above-mentioned study.

Approval is granted for one year till the 28 October 2013.

Please submit a progress form, using the standardised Annual Report Form, if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please quote the HREC. REF in all your correspondence.

Yours sincerely

Signature removed

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

sAriefdien

L. NIMR Ethical Clearance

THE UNITED REPUBLIC OF TANZANIA

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NIMR/HQ/R.8a/Vol. IX/1481

Ministry of Health and Social Welfare
P.O. Box 9083
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Tel: 255 22 2120262-7
Fax: 255 22 2110986

28th February, 2013

Mr. Elvis Joseph Miti
University of Cape Town
C/o PASADA
P. O. Box 70225
Dar es Salaam
Tanzania

CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: An evaluation of a psychosocial intervention for Orphans on HIV treatment; A phase II RCT of memory work therapy at PASADA Tanzania (Miti E. J. *et al*), has been granted ethical clearance to be conducted in Dar es Salaam, Tanzania.
The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health & Social Welfare and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine. NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Approval is for one year: 28th February, 2013 to 27th February, 2014.

Name: Dr Mwelecele N Malecela

Signature removed

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Name: Dr Donan Mmbando

Signature removed

Signature
ACTING CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, SOCIAL WELFARE

CC: RMO
DMO